Assessment of participation in people with a mild intellectual disability

Studies from The Swedish Institute for Disability Research 55

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Abstract

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The overall aim of this doctoral thesis was to explore an assessment of participation according to the International Classification of Functioning, Disability and Health (ICF) in people with a mild intellectual disability.

Study I used secondary data and explored how participation can be assessed. Study II-IV explored participation empirically regarding 68 everyday activities from all nine life domains according to the ICF. Study II explored assessment of self-rated participation by investigating to what extent perceived ability, actual performance and perceived importance correlated. Study III-IV explored the contribution of perceived importance to an assessment of participation; study III by investigating frequencies of everyday activities regarding performance and importance separately as well as regarding combined measures of performance and perceived importance, and study IV by comparing proxy ratings with self-rated measures regarding ability and measures of participation. Study III also correlated measures of participation with a single-item measure of subjective general well-being and study II and IV investigated internal consistency in terms of Cronbach's alpha. Study II and III included 55 and 69 individuals with intellectual disability respectively. Study IV included 40 individuals with intellectual disability and 40 proxy persons. The informants from the target group were partly the same.

Study II and IV supported the suggestions from study I that participation should be assessed by self-ratings and study II found that this is an appropriate method also to people with a mild intellectual disability. Study III showed that participation is related to subjective well-being. Study III-IV found somewhat different results if measuring participation as performance solely or as a combination of performance and perceived importance. Overall, the results of the thesis suggest that performance solely might be sufficient to assess participation at a group level but in a clinical context, when the knowledge of a certain individual is of interest, the perceived aspect of involvement is necessary to include in an assessment of participation.

Keywords: Assessment, clinimetrics, ICF, intellectual disability, participation, participation restrictions, self-ratings.

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List of studies

The present doctoral thesis is built on the following studies:

I. Granlund M, Arvidsson P, Niia A, Björck-Åkesson E, Simeonsson R, Maxwell G, Adolfsson M, Eriksson-Augustine L, Pless M. (2012). Differentiating Activity and Participation of Children and Youth with Disability in Sweden - A Third Qualifier in ICF-CY: American Journal of Physical Medicine Rehabilitation, 91, 84-96.

II. Arvidsson P, Granlund M, Thyberg I, Thyberg M. (2012). International Classification of Functioning, Disability and Health categories explored for self-rated participation in Swedish adolescents and adults with a mild Intellectual disability. Journal of Rehabilitation Medicine, 7, 44, 562-569.

III. Arvidsson P, Granlund M, Thyberg I, Thyberg M. (accepted). Important aspects of participation and participation restrictions in people with a mild intellectual disability. Disability and Rehabilitation.

IV. Arvidsson P. (submitted). The relation between proxy-ratings and self-ratings of participation in people with a mild intellectual disability. Journal of Policy and Practice in Intellectual Disability.

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Table of contents

INTRODUCTION 13

APPROACHES TO DISABILITY 15
Individual approaches 15
Environmental approaches 15
Integrative approaches 16
Endorsing an integrative approach to disability 17

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF) 19

ASSESSING PARTICIPATION ACCORDING TO THE ICF 21
The participation concept 21
Participation according to the ICF 21
Involvement 22
Life situations 23
Self-ratings 24

INTELLECTUAL DISABILITY 26
What is intellectual disability? 26
An integrative approach to intellectual disability 27
ICF and AAIDD 28
Adaptive behaviour and participation 29
Problems related to an integrative approach to intellectual disability 29
Perceived needs 30
Individualized support 31

AIMS OF THE DOCTORAL THESIS 33

SPECIFIC AIMS OF EACH STUDY 34

GENERAL METHODOLOGICAL CONSIDERATIONS 35
Ethics 36

METHODS OF THE EMPIRICAL STUDIES 37
Study I 37
Study II-IV 37
Inclusion process and informants, study II-IV 37
Materials and data collection, study II-IV 38
The participation questionnaire *38*
Measures of ability, performance and importance *39*
General subjective well-being (study III) *40*

Intelligence quaint (IQ) *40*
Data exploration, study III and IV 40
Dichotomization of data *40*
Measures of ability, performance and importance *41*
Measures of important participation and important participation restriction *41*
Data analysis, study II-IV 41
Internal consistency *41*
Correlations *41*
Ranking lists of items *42*
Differences between self-ratings and proxy-ratings *42*

SUMMARY OF EMPIRICAL STUDIES 43
Study I. Differentiating Activity and Participation of Children and Youth with Disability in Sweden - A Third Qualifier in ICF-CY 43
Aim 43
Method 43
Results 43
Conclusion 43
Study II. International Classification of Functioning, Disability and Health categories explored for self-rated participation in Swedish adolescents and adults with a mild Intellectual disability. 45
Aim 45
Method 45
Results 45
Conclusion 46
Study III. Important aspects of participation and participation restrictions in people with a mild intellectual disability 47
Aim 47
Method 47
Results 47
Conclusion 48
Study IV. The relation between proxy-ratings and self-ratings of participation in people with a mild intellectual disability 49
Aim 49
Method 49
Results 49
Conclusion 50

MAIN RESULTS 51
How can participation according to the ICF be assessed? 51
What is the contribution of a measure of perceived importance to an assessment of participation? 52

What is the relation between proxy ratings and self-ratings of performance and importance as well as of 'important participation' and 'important participation restrictions'? 53

METHODOLOGICAL DISCUSSION 55
Participants 55
Measures 56
The selection of items 56
The three-grade scale 59
Correlations to well-being 59

GENERAL DISCUSSION 60
Assessing participation 60
The integrative approach 61
Activity and participation 62
The contribution of perceived importance 63
Participation and general well-being 65
What is "full" participation? 66
The relation between self-ratings and proxy ratings 67
Performance and importance 67
Ability 68

CONCLUSIONS 69

SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH) 70
Varför har avhandlingen gjorts? 70
ICF och delaktighet 71
Kort beskrivning av avhandlingens metod 72
Deltagare 72
Mätinstrument 72
Analyser 72
Avhandlingens viktigaste resultat 73
Avhandlingens viktigaste slutsatser 73
Bilaga till den svenska sammanfattningen - de 68 aktiviteterna indelade efter livsområden 75

ACKNOWLEDGEMENTS 76

REFERENCES 79

Introduction

People with intellectual disability are at high risk for physical and psychological health problems, and participation restrictions. People with a mild intellectual disability perceive more health problems than people without intellectual disability (Walsh, 2008; Snell et al., 2009; Thompson et al., 2009; Greenspan, Switzky & Woods, 2011; Schalock, 2011). The term *mild* refers to less cognitive impairments in comparison with people with a moderate or a profound intellectual disability and thus not to mild problems in everyday life.

In a Swedish context, comparisons of living conditions between people with a mild intellectual disability and the general population show differences in almost every life domains, particularly regarding work, income and social life (Tideman, 2000; Umb-Carlsson & Sonnander, 2005). People with a mild intellectual disability do often rely on financial support through the social insurance system and have low influence on their financial situation. Another major problem for individuals with a mild intellectual disability is that their social life is often restricted. They mostly interact socially with relatives and/or staff only and few have real friends that they have chosen by themselves (Tideman, 2000; Umb-Carlsson & Sonnander, 2005).

For people with a mild intellectual disability, appropriate individualized support can enhance functioning in everyday life. Individualized support, as from clinical services, will improve general well-being and general health and thus reduce the likelihood for participation restrictions (Simeonsson, Leonardi, Lollar et al., 2003; Arvidsson, Granlund & Thyberg, 2008; Snell et al., 2009; Thompson et al., 2009; Stuart, 2012). Individuals with intellectual disability have legal right to support. However, they do not necessarily perceive the existing support as available (Snell et al., 2009; Maxwell, Alves & Granlund, 2012a). This might be due to for example problems in being aware of personal limitations as well as difficulties in expressing their needs verbally (Greenspan et al., 2011; Schalock, 2011). As a consequence, individuals with a mild intellectual disability are often at the mercy of trusting proxy-persons (e.g. family members or support workers) (Perry & Felce, 2002; Claes, Vandevelde, Van Hove, van Loon & Schalock, 2012a). Therefore, a main issue in clinical services for people with a mild intellectual disability is to develop methods to get accurate knowledge about the needs and preferences of the individual (Eriksson & Granlund, 2004a; Snell et al., 2009; Claes et al., 2012a; Claes, Van Hove, Vandevelde, van Loon, Verschelden & Schalock, 2012b). Hence, there are methodological challenges to develop assessments that facilitates for the individual to express their own perceived needs and demands without relying on proxy-persons (Arvidsson et al., 2008; Thompson et al., 2009; Eyssen, Steultjens, Dekker & Terwee, 2011; Claes et al., 2012a).

The International Classification of Functioning, Disability and Health (ICF) provides an integrative approach to disability and the ICF participation concept is assumed to reflect the functional interplay between the body functions of an individual and the everyday environment (WHO, 2001). This approach to disability is also relevant for people with intellectual disability (AAIDD 2010). In the ICF, *participation* is defined as involvement in a life situation and *participation restrictions* as experienced problems in life situations (WHO, 2001). Participation and participation restrictions are assumed to reflect the individuals' perception of health and disablement. The qualifier *performance* is suggested as an appropriate evaluator of participation but there is no concrete guidance to how participation/participation restrictions should be assessed.

The performance qualifier can provide information only on whether an individual actually attends to an activity or not. Many researchers and clinicians have raised a need for an explicit perceived aspect of involvement, a qualifier reflecting the perceived values of the individual (Nordenfelt, 2003; Perenboom and Chorus, 2003; Ueda & Okawa, 2003; Wade & Halligan, 2003; Hemmingsson & Jonsson, 2005; Reed et al., 2005; Nordenfelt, 2006; Arvidsson et al., 2008; Whiteneck & Dijkers, 2009; Levasseur, Richard, Gauvin & Raymond, 2010; Eyssen et al., 2011; Coster, Law, Bedell, Khetani, Cousins & Teplicky, 2012; Falkmer, Granlund, Nilholm & Falkmer, 2012; Maxwell et al, 2012a; Maxwell, Granlund & Eriksson-Augustine, 2012b).

The overall aim of this doctoral thesis was to explore an assessment of participation according to the ICF in people with a mild intellectual. The thesis consists of four studies with specific aims that together contribute to the overall research questions: How can participation according to the ICF be assessed? What is the contribution of a measure of perceived importance to an assessment of participation? What is the relation between proxy ratings and self-ratings of performance and importance as well as of 'important participation' and 'important participation restrictions'?

Approaches to disability

Throughout the history of disability there has not been any consensus about definitions and conceptualizations (Bickenbach, Chatterji, Badley & Üstün, 1999; Gustavsson, 2004; Shakespeare, 2006; Thyberg, Nelson & Thyberg, 2010) but approaches to disabilities can, somewhat simplified, be divided into individual, environmental and interactional/integrative approaches.

Individual approaches

Individual approaches to disability focuses primarily pathology and deficits within the individual (Simeonsson, Granlund, & Björck-Åkesson, 2006; Shakespeare, 2006; Buntinx & Schalock, 2010; Thyberg et al., 2010). The deficits might cause different levels of disability in different environmental settings but the explanation is always associated with bodily limitations related to diseases, injuries and congenital disorders (Thyberg et al., 2010). Disability is always considered as a result of a problem within the human body (i.e. an impairment or activity limitation) and disability services are focusing on medical, psychological or educational treatment of the individual (Gustavsson, 2004; Shakespeare, 2004; Tøssebro, 2004; Leclair, Leclair & Brigham, 2009). The individual approach to disability was expressed in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980) which described a unidirectional connection between functional impairments and disability (Nordenfelt, 1983; Tøssebro, 2004; Shakespeare, 2006; Leclair et al., 2009). Also, an individual approach to disability can be found in social practices such as the social insurance systems of many countries (Nordenfelt, 2008). According to an individual approach, a disability always requires deficiency and/or impairment at a bodily level (WHO, 1998; Gustavsson, 2004; Shakespeare, 2004; Leclair et al., 2009; Thyberg et al., 2010).

Environmental approaches

For a long time, the individual approaches have been criticized because of their negligence of the contextual aspects in the disablement process (Gustavsson, 2004; Oliver & Barnes, 2010; Thyberg, 2010). This criticism culminated when environmental approaches to disability were articulated in which the role of environmental and societal features as causal factors of the disablement process were emphasised (Gustavsson, 2004; Shakespeare, 2004; Tøssebro, 2004; Oliver & Barnes, 2010). According to some environmental approaches, disability is described in terms of discrimination and explained in terms of problems associated with general human rights (Shakespeare, 2004; Tøssebro, 2004; Oliver & Barnes, 2010; Stuart, 2012). Thus, non-individualized policies, such as disability rights and anti-discrimination legislation, are at focus for interventions (Gus-

tavsson, 2004; Shakespeare, 2004; Tøssebro, 2004; Stuart, 2012). Environmental approaches make a sharp distinction between deficits related to the individual, i.e. impairments which have to do with the body, and problems the individual may perceive in relation to the everyday context and society (Gustavsson, 2004; Shakespeare, 2004; Tøssebro, 2004).

One form of an environmental approach to disability, often referred to as the *strong social model* (Shakespeare, 2004), stresses that disability is, without exceptions, a consequence of a non-adapted society which systematically creates barriers for people with impairments (Gustavsson, 2004; Shakespeare, 2004; Tøssebro, 2004). However, a *weak social model*, considers disability as problems related to the individual's interaction within the environment (Gustavsson, 2004; Shakespeare, 2004; Shakespeare, 2006). The latter form of social model is quite similar to an interactional/integrative approach to disability (WHO, 2001; Gustavsson, 2004; Shakespeare, 2004; Thyberg et al., 2010; Stuart, 2012).

Integrative approaches

An integrative (or interactional) approach to disability can be described as a combination of the individual and environmental approaches (Gustavsson, 2004; Hurst, 2003; Shakespeare, 2004; Thyberg et al., 2010). This may be considered as a paradox since 'strong' versions of both individual and environmental approaches are, at least theoretically, impossible to combine; strong individual approaches explain disability solely as an effect of an impaired body and strong environmental approaches explain disability solely as a consequence of an oppressive society (Danermark, 2001; Gustavsson, 2004; Shakespeare, 2004; Shakespeare, 2006). In this matter, the strong approaches to disability, whether they are individual or environmental, may be regarded as reductionist and in both cases essential aspects of disability will be neglected (Danermark, 2001; Gustavsson, 2004; Bhaskar & Danermark, 2006), most obviously the person's interaction within his/her everyday context will be ignored (Thyberg et al., 2010). The integrative approach is a question of both individual and environmental features, rather than either or (Danermark, 2001; Gustavsson, 2004; Bhaskar & Danermark, 2006). According to the ICF integrative approach, disability is used as an umbrella term covering impairments, activity limitations and participation restrictions. It is important to be aware that this terminology is quite different from the terminologies of both the tripartite ICIDH and the bipartite social models, in which there a distinction between disability and impairments of body functions (WHO, 2001; Shakespeare, 2006; Badley, 2008; Thyberg et al., 2010; Sverker, Östlund, Thyberg, Waltersson & Thyberg et al., in press). Disability is considered as a result of both barriers in the environment and problems related to the body and interventions can focus on both the person and/or the context, as well as on the person's interaction within his/her context (WHO, 2001; Sime-

onsson et al., 2006; Wehmeyer et al., 2008; Buntinx & Schalock, 2010; Stuart, 2012).

Endorsing an integrative approach to disability

In many clinical practices dealing with disability, the 'conflict' between individual and environmental models to disability has probably not been regarded as an important issue because some kind of integrative approach has actually been used. Since at least 1912, when Swedish precursors of rehabilitation medicine published an explicit integrative definition disability (Haglund, 1912; Thyberg et al., 2010), practitioners have probably taken societal and economic aspects of the environment into account to understand and intervene on disabilities (Thyberg, 2004, Shakespeare, 2006; Leclair et al., 2009). Although a medical or clinical model of disability has often been considered as synonymous with an individual approach to disability, historical findings rather implicate medical and clinical models of disability as taking the interaction between the individual and environment into account (Shakespeare, 2004; Shakespeare, 2006; Leclair et al., 2009; Thyberg et al., 2010). The assumed equalization between a medical or clinical approach to disability and an individual approach may in part be due to an failure to make a distinction equalization between a medical model of disability and a medical model of disease (Haglund, 1912; AMA, 2008; Leclair et al., 2009; Thyberg et al., 2010) and in part to an equalization between explicit models of disability and for example the wide range of clinical practices that are not rehabilitation practices but other health care practices with a focus on the prevention or cure of disabling diseases (WHO, 2001, footnote 16, p 20; Thyberg, 2004; Stucki, Cieza & Melvin, 2007).

In international policy documents, an integrative approach to disability has been highlighted been highlighted since at least the 1990s in 'Standard rules on the equalization of opportunities for persons with disabilities' (UN, 1994; Tøssebro, 2004) and later on in the United Nation's 'Convention on the rights of persons with disabilities' (Tøssebro, 2004; UN, 2006; Stuart, 2012). The standard rules stated the socio-political conditions for achieving equality, autonomy, non-discrimination, participation, and inclusion in society and the convention underlines that persons with disabilities should be able to participate fully in all aspects of life such as: rights (access and privacy); participation; autonomy; physical wellbeing; material well-being (work/employment); social inclusion; emotional well-being (freedom from exploitation, violence, and abuse); and personal development (education, habilitation and rehabilitation) (UN, 2006; Buntinx & Schalock, 2010; Stuart, 2012).

This thesis endorses an integrative approach to disability which also raises some important theoretical and methodological challenges, for example to handle bodily and societal aspects simultaneously (Danermark, 2001; Gustavsson,

2004; Molin, 2004; Bhaskar & Danermark, 2006; Simeonsson et al., 2006). According to for example critical realism, the understanding of disability can neither be reduced only to a social nor a bodily level (Danermark, 2001; Bhaskar & Danermark, 2006). Instead, disability is considered to be understood by a stratified multi-level model (Danermark, 2001; Gustavsson, 2004; Tøssebro, 2004). Hence, interaction between for instance individual and social aspects is understood in terms of an interaction between different levels of reality (Danermark, 2001; Gustavsson, 2004; Bhaskar & Danermark, 2006). Each level (societal, psychological, biological or molecular) has its own mechanisms and works on its own premises and each level must develop its own methodologies and theories (Danermark, 2001; Gustavsson, 2004; Danermark & Bhaskar, 2006).

In order to facilitate the empirical investigation of what combination of aspects that might be related to disability, the ICF provides an integrative and interactional framework including both individual and environmental factors (WHO, 2001; Gustavsson, 2004; Larsson-Lund & Lexell, 2009).

International Classification of Functioning, Disability and Health (ICF)

Adhering to an integrative definition of disability, the ICF provides a framework that guides health and medical professionals in understanding human functioning as an interaction between individual and environmental factors (Bickenbach et al., 1999; WHO, 2001; Üstün, Chatterji, Bickenbach, Kostanjsek & Schnieder, 2003; Reed et al., 2005; Thyberg et al., 2010). The ICF is a system for describing, but not diagnosing, functioning through biological/bodily and social/environmental perspectives of health (WHO, 2001; Ditterline & Oakland, 2009; Thyberg et al., 2010). According to the ICF, *functioning* is an umbrella term including *body functions*, *activity* and *participation*. *Body functions* are physiological functions of biological systems (including the brain and psychological functions). *Body structures* are anatomic parts of the body such as organs and limbs. *Activity* is the execution of a task or action by an individual. *Participation* is defined as involvement in a life situation. In ICF, the component *disability* is an umbrella term for *impairments*, *activity limitations* and *participation restrictions*. *Impairments* are problems in body functions. *Activity limitations* are difficulties an individual may have in executing activities. *Participation restrictions* are problems an individual may experience in involvement in life situations. Impairment, activity limitation and participation restriction are not identical (WHO, 2001; Leclair et al., 2009). For example, an individual may have impairment and activity limitations but be able to participate in a relevant life situation. On the contrary, an individual may have no (or minor) impairments and activity limitations but yet inability to participate (Leclair et al., 2009) which both might be due to environmental factors (WHO, 2001; Arvidsson et al., 2008; Leclair et al., 2009). The ICF also provide a category of *environmental factors* to which the individual interacts. The environmental factors are factors such as support, attitudes and policies. Also, a category of *personal factors* such as gender, class and cultural background is provided however not classified in the ICF (WHO, 2001; Leclair et al., 2009).

The ICF component activity/participation is organized into nine different life domains (WHO, 2001). According to ICF, the term activity is considered as reflecting an individual's execution of a task in an assumed standardized environment and participation is considered as an individual's actual performance in different life domains. However, the component activity/participation are provided in a common list (WHO, 2001; Perenboom & Chorus, 2003; McConachie, Colver, Forsyth, Jarvis & Parkinson, 2006). Earlier drafts of the ICF considered activity and participation as two different dimensions but this distinction was difficult to verify empirically (Perenboom & Chorus, 2003; Reed et al., 2005). Instead, one important idea of the ICF is the possibility for a researcher to focus

on either activity or participation, or both (WHO, 2001). Depending on the purpose, it is also possible to study the same domains or other domains from the same list in terms of activity and participation (WHO, 2001; Stucki et al., 2007; Gleason & Coster, 2012).

The child and youth version of the ICF, the ICF-CY, is basically equal to the ICF with some additional functions and problems related to development, behaviour and contexts in the first 20 years of a person's life (WHO, 2007).

Assessing participation according to the ICF

The participation concept

According to the goal statements of services organizations in the health and education sectors, the participation construct is central but has been given several different definitions and has been operationalized in several different ways (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996; Law, 2002; Almqvist & Granlund, 2005; Hemmingsson & Jonsson, 2005; Adolfsson, Malmqvist, Pless & Granlund, 2011; Coster et al., 2012; Eyssen et al., 2011; Maxwell, 2012c; Hwang et al., 2013). The need to provide clarity on the participation construct is currently well debated (McConachie et al., 2006; Badley, 2008; Coster & Khetani, 2008; Eyssen et al., 2011; Coster et al., 2012). Among several definitions and conceptualizations, participation is described as a complex concept in which many physical, social, emotional as well as environmental factors are included, and participation is described either with reference to a personal characteristic or to interplay between the individual and the environment (Gustavsson, 2004; Molin, 2004; Eyssen et al., 2011). For example, participation has been defined in term related to "handicap" indicating disadvantages, which limits or prevents an everyday action that is normal for an individual (Eyssen et al., 2011). Participation has also been defined in term related to "disability" indicating limitations to perform activities in social context (Eyssen et al., 2011). The environment itself, as a necessary condition and 'scene-setter' as well as a context that facilitates or hinders participation, is an intrinsic part to understand what participation is (WHO, 2001; Badley, 2008; Eyssen et al., 2011). Common to most definitions of participation are that they either contain an aspect of *actual attendance* in everyday situations or contain an aspect of *perceived involvement* (Maxwell, 2012c). The attendance aspect of participation usually contains dimensions such as the opportunity or actual accessibility to perform a certain action and the perceived aspect usually contains dimensions such as volition and perceived importance to perform (Nordenfelt, 2003; Reed et al., 2005; Nordenfelt, 2006; Maxwell et al, 2012b). Thus, for different life situations, *perceived involvement* can described in terms of will, engagement or intensity of performing an action and *actual attendance* can be described as observed frequency or actual performance (Simeonsson, Carlson, Huntington, McMillen & Brent, 2001; Eriksson & Granlund, 2004a; Nordenfelt, 2003; Molin, 2004; Arvidsson et al., 2008; Maxwell & Granlund, 2011; Maxwell et al, 2012b).

Participation according to the ICF

According to the ICF, participation is assumed to reflect the functional interplay between the body functions (of an individual) and the everyday environment. In

the ICF, the definition of participation is *involvement in a life situation*. Participation restrictions are defined as experienced problems in life situations and are assumed to reflect the individuals' perception of disability (due to impairments of body functions, and/or activity limitations and/or environmental hindrances). The qualifier *performance* is suggested as an appropriate evaluator of the involvement (WHO, 2001). However, the ICF underlines that actual performance is not necessarily equal to participation but that actual performance should be distinguished from the subjective experience of involvement it is not clearly described whether the subjective aspect should be included in participation according to ICF or not (WHO, 2001, footnote 14, p 15).

The relation between the concepts activity and performance has been debated (Badley, 2008; Coster & Khetani, 2008; Klang, 2012; Maxwell, 2012c). In addition to the ability or capacity to perform activities, the ICF provides a possibility to describe activity as the actual performance of activities in an individual perspective. However, bipartite social models of disability do not recognize a decontextualized individual perspective but rather emphasize that an execution of a task is always in a context (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006; Sverker et al., in press). Instead, to distinguish between the *ability* to execute a task from the *actual performance* seems reasonable, also in the perspective of bipartite social models of disability, as long as both the ability and the performance are considered to take part in a context (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006; Sverker et al., in press). The ICF emphasizes that the ability to perform has to be separated from the actual performance. However, it is not clearly described if the concept of ability implies a context or not. Adhering to an integrative approach to disability, that does not recognize a decontextualized individual perspective, this thesis does not use a split between the ICF conceptions of activity in an individual perspective and participation in a societal perspective, all in accordance with option 4 of annex 3 of the ICF (WHO, 2001; Sverker et al., in press). It is assumed that this option is included in the ICF in order to pay attention to possible theoretical advantages of bipartite models of disability. However, the relation between ability and actual performance is still at interest. In a context, the relation between ability and performance can possibly be considered as a continuum with ability at the first end-point, via actual performance, to perceived involvement at the other end-point (Simeonsson, et al., 2001; Gustavsson, 2004; Molin, 2004; Arvidsson et al, 2008; Maxwell, 2012c).

Involvement

The performance qualifier can provide information only on whether an individual actually attends to an activity or not, and many researchers raise a need for an explicit perceived aspect of the performance, i.e. a third qualifier which is re-

flecting perceived values of the individual (Nordenfelt, 2003; Perenboom and Chorus, 2003; Ueda & Okawa, 2003; Wade & Halligan, 2003; Hemmingsson & Jonsson, 2005; Reed et al., 2005; Nordenfelt, 2006; Arvidsson et al., 2008; Whiteneck & Dijkers, 2009; Levasseur et al., 2010; Eyssen et al., 2011; Coster et al., 2012; Falkmer et al., 2012; Maxwell et al., 2012b; Stuart, 2012). For treatment planning, identification of interventions to facilitate the requested functioning (e.g., individual treatment, environmental modification, or some combination) is the most critical issue (Reed et al., 2005). Thus, if assessing participation, it might not only be important to separate between ability and performance, but also to separate between ability and the individuals' perceived importance and volition to perform a certain activity (Reed et al., 2005). Hence, there is a need for a perceived aspect of involvement that could be combined with the performance qualifier (Nordenfelt, 2003; Perenboom and Chorus, 2003; Ueda & Okawa, 2003; Wade & Halligan, 2003; Reed et al., 2005; Nordenfelt, 2006; Coster et al., 2012; Maxwell et al., 2012b). Thus, to obtain such assessment of participation, a reasonable methodology is to investigate the relations between perceived ability, performance and perceived importance.

Life situations

Even though the activity and participation components are handled as separate dimensions in the ICF they are provided in a single list of life situations of which any may be coded as activity or participation or both (WHO, 2001; Reed et al., 2005; Gleason & Coster, 2012). The term life situation is not explicitly conceptualized in the ICF, however, the list is considered to include both everyday *conditions* as well as *sequences of actions* which occur regularly in a person's life within an everyday context (McConachie, et al., 2006; Coster & Khetani, 2008; Badley, 2008; Adolfsson et al., 2011). There might be a dilemma to separate the condition from the action (Adolfsson et al., 2011). If recognizing that tasks and actions are always executed in a context, albeit to different degree of complexity, the list of life situations can basically be considered as different actions that people can perform (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006; Sverker et al., in press). Then the researcher can focus on the ability, on the actual performance, and on the perceived aspect of involvement.

According to the ICF, life situations include aspects of learning and applying knowledge such as making decisions, general tasks such as managing daily routine and handling responsibilities, communication such as starting a discussion or conversation, mobility such as moving around using transportation, self-care, domestic life such as acquiring a place to live, interpersonal interactions such as forming relationships, performance in major life areas such as education, work and economic life, involvement in community life such as recreation, religion, human rights, political life and citizenship (WHO, 2001). According to the ICF

manual, these life situations are organized into nine domains: 1) Learning and applying knowledge, 2) General tasks and demands, 3) Communication, 4) Mobility, 5) Self-care, 6) Domestic life, 7) Interpersonal interactions and relationships, 8) Major life areas, 9) Community, social and civic life. The domains are listed and structured on an approximate order of increasing complexity with respect to expected sequences of actions and interactions with the social environment, both regarding the order of domains and within domains (Badley, 2008). Thus, the whole list of possible categories of participation is quite complex and heterogeneous (Coster & Khetani, 2008).

To assess *life situations*, and also to obtain a clinically applicable instrument, it is necessary to make a selection of items from the extensive lists of ICF categories (including approximately 120 life situations at the second level of classification), and perhaps also a selection among the nine domain of participation (WHO, 2001). To maintain the width and multi-dimensionality of the participation concept, however, no a priori assumptions that certain "basic" domains of participation should not be regarded as possible aspects of participation and involvement in life situations were made in this thesis. As mentioned above, this approach is compatible with option 4 according to Annex 3 of the ICF (WHO, 2001). This approach does also take the argument from the social model into account, that no actions should be decontextualized but rather considered as either ability or disability in a context (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006; Sverker et al., in press).

An important question is whether a measure based on a selection of items will reflect a common construct, i.e. participation (Badley, 2008; Coster & Khetani, 2008). If the domains mainly reflect commonalities with respect to what people would be expected to be able to do, this would not necessarily be the most important factor influencing the consistency of measures focusing on the actual performance, which will also be influenced by for example what activities are perceived to be important in the perspective of an individual (Badley, 2008; Coster & Khetani, 2008). In addition to questions concerning the appropriate selection of items from the activity/participation list, one may question how participation should be rated in terms of for example performed activity, frequency of performance, or subjective engagement operationalized as perceived importance.

Self-ratings

Performance, operationalized as either frequency of being in the situation and performing the activity or how an activity is performed in the situation, can be measured using ratings and reports from others just as well as with self-assessment (Reed et al., 2005). However, it is unlikely that the subjective experience of involvement can be measured with ratings made by others or observa-

tions (Reed et al., 2005). To provide a truly valid basis for an assessment of participation that also includes the perceived aspect of involvement, it should be consistent with the perspectives of the persons whose participation are attempted to be characterized. The best judgement of participation might therefore be obtained from the individual by self-ratings rather than from a professional or proxy-person (Perenboom & Chorus, 2003; Coster & Khetani, 2008; Walsh, 2008; Arvidsson et al., 2008; Claes et al., 2012a), and even in people with a mild intellectual disability it is possible to collect self-reported data provided the measurement method is adapted to their cognitive abilities (Arvidsson et al., 2008; Hartley & MacLean, 2008; Claes et al., 2012a).

Intellectual disability

What is intellectual disability?

To meet the diagnostic criteria of intellectual disability, the three following criteria have to be met: 1) the developmental criteria; i.e. intellectual disability originates during the developmental period, before age 18, 2) the intellectual criterion (significant limitations in intellectual functioning), and 3) the adaptive behaviour criterion (significant limitations in understanding and handling environmental expectations and demands) (DSM-IV, 2000; AAIDD, 2010). More specifically, significant limitations in intellectual functioning is an IQ score that is approximately two standard deviations below the mean (i.e. IQ below 70) considering the standard error of measurement for the specific instruments used and the instruments' strengths and limitations. Although the two standard deviations below the mean criterion might be considered arbitrary, it has been used widely since 1973 (Buntinx & Schalock, 2010; Greenspan et al., 2011). Analogously, the limitations in adaptive behaviour is approximately two standard deviations below the mean of either (a) one of the following three types of adaptive behaviour: conceptual, social, or practical; or (b) an overall score on a standardised measure of conceptual, social, and practical skills (Buntinx & Schalock, 2010; Greenspan et al., 2011).

The prevalence of intellectual disability is around 1% (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011). The prevalence is almost two times more in low and middle income countries compared to high income countries, and the highest prevalence is in child and adolescent population (Durkin, 2002; Maulik et al., 2011). The group with a mild intellectual disability constitute about 80% to 90% of all individuals with intellectual disability (Snell et al., 2009). Individuals with intellectual disability are most often identified and diagnosed in early school-years, partly because of the cognitive and social demands of school, but also because of that the school systems in most countries have the financial and methodological resources as well as the legal assignment to recognise disabilities in all children (Snell et al., 2009; Maulik et al., 2011).

There is a considerable variation of existing terms for classifying people with intellectual disability such as mental deficiency, mental handicap, mental subnormality, developmental disability, and learning disabilities (Greenspan, 1999; Brown and Gordon, 2007; AAIDD, 2010; Schalock, 2011). However, the term intellectual disability is the most consistent with international terminology, including journal titles, published research, and organisation names (Schalock, Luckasson, & Shogren, 2007; Wehmeyer et al., 2008; AAIDD, 2010; Schalock, 2011).

An integrative approach to intellectual disability

There is debate whether intellectual disability should be conceptualized along with a disorder approach or an integrative approach to disability (Buntinx & Schalock, 2010; Greenspan et al., 2011; Schalock, 2011; Salvador-Carulla et al., 2011). Advocates of the *disorder approach* suggest intellectual disability to be conceptualized in terms of bodily impairments, especially as cognitive deficits and/or brain disorders (Buntinx & Schalock, 2010; Greenspan et al., 2011; Schalock, 2011; Salvador-Carulla et al., 2011). Intellectual disability is considered as a health condition, or a disease, and the main issues related to research is about biology and etiology. Clinical practices are often focusing on individual interventions such as cognitive training and/or individualized adaptions (AMA, 2010; ICD-10/ICD-11). In terms of the ICF and somewhat simplified, the focus is at a bodily level and the overall aim is to relieve activity limitations by interventions on impaired functions.

Advocates of the *integrative approach* suggest that intellectual disability should be conceptually associated with the current integrative and interactional frameworks of disability such as the ICF (WHO, 2001; Buntinx & Schalock, 2010; Greenspan et al., 2011; Schalock, 2011; Salvador-Carulla et al., 2011). One important idea of the ICF is to not consider disability as a result of either an impaired body or societal barriers but rather as an interaction of both (WHO, 2001), and according to an integrative approach, intellectual disability can be described as a multidimensional state of functioning rather than a permanent health condition (AAIDD, 2010).

The AAIDD describes intellectual disability as a multi-dimensional state of functioning which should be enhanced by individualised support (Aronowitz, 1998; Wehmeyer et al., 2008; Thompson et al., 2009; Buntinx & Schalock, 2010; Schalock et al., 2010; AAIDD, 2010; Schalock, 2011). This conception of intellectual disability is consistent with an integrative conceptualization of disability (WHO, 2001; Schalock et al., 2007; Wehmeyer et al., 2008; Schalock, 2011). The AAIDD model emphasizes an integrative, interactional and multidimensional understanding of intellectual disability (AAIDD, 2010; Simeonsson et al., 2006; Wehmeyer et al., 2008). The AAIDD recognizes the biological and social complexities associated with intellectual disability and also the significant role that individualized supports play in improving functioning (Greenspan & Switzky, 2006; Simeonsson et al., 2006; Thompson et al., 2009; AAIDD, 2010). Intellectual disability, as a state of functioning, can be affected by both bodily functions/impairments (such as limitations in intellectual functions) and by circumstances in the environment. Thus, supportive interventions can focus on a bodily/individual level, on a contextual level and/or on for example societal interaction (Reed et al., 2005; Stucki et al., 2007; Arvidsson et al., 2008; Thompson et al., 2009; AAIDD, 2010).

According to the AAIDD, intellectual disability has come to be seen as not just a significant limitation in intelligence and adaptive skills. Rather it is viewed as a problem of the whole person in his/her life situation and the problem influences health, community participation and the entire roles that the person plays in society (Buntinx & Schalock, 2010). Intellectual disability is therefore not considered as an absolute, invariant trait or deficit of the individual but rather as functional limitations in individual actions performed within the society (Greenspan & Switzky, 2006; Wehmeyer et al., 2008; Buntinx & Schalock, 2010; Schalock, 2011). The view to what intellectual disability is has thereby developed from focusing on pathology or deficits within the person to an increased understanding of the role played by the societal environment in the process of disablement and its enhancement (Wehmeyer et al., 2008; AAIDD, 2010; Buntinx & Schalock, 2010; Schalock, 2011).

ICF and AAIDD

As proposed by the WHO (2001) and AAIDD (Buntinx & Schalock, 2010; Schalock, 2011) human functioning is an umbrella term for all life activities. The ICF model of human functioning involves six components: health condition, body functions and structures, activities, participation, environmental factors, and personal factors (WHO, 2001). The AAIDD model includes five components of human functioning (intellectual abilities, adaptive behaviour, health, participation, and context) and focuses on the key role played by individualised supports in enhancing the level of human functioning (AAIDD, 2010; Buntinx & Schalock, 2010). Despite there are some obvious similarities between the ICF and the AAIDD models of human functioning, the main difference between ICF and AAIDD is related to that the AAIDD model is developed as a particular model for intellectual disability (Schalock et al., 2007; Ditterline & Oakland, 2009; AAIDD, 2010; Buntinx och Schalock, 2010; Schalock, 2011; Gleason & Coster, 2012). The AAIDD system contains professional guidelines for diagnosis and classification and for the assessment of functioning along the five dimensions (intellectual abilities, adaptive behavior, health, participation, and context). Furthermore, whereas supports in the ICF are implied in the environmental factors, the AAIDD model defines supports as a distinct and major component of the model (WHO, 2001; AAIDD, 2010). The AAIDD considers support as a key factor in the enhancement of individual functioning and an integral part of the assessment process. Moreover, although the AAIDD model advocates assessment of for example societal participation, needs and existing support, there is no explicit methodological guidance to how integrative and/or environmental concepts should be assessed nor related to the diagnosis of intellectual disability (Greenspan et al., 2011; Salvador-Carulla et al., 2011).

Adaptive behaviour and participation

There is also an overlap between the concepts of adaptive behaviour (AAIDD) and participation (ICF) (Arvidsson et al., 2008; Ditterline & Oakland, 2009; Buntinx & Schalock, 2010; Schalock, 2011; Gleason & Coster, 2012). Although the AAIDD and the ICF are intended to be used for various purposes, the AAIDD suggest that both adaptive behaviour and participation in everyday life should be assessed in connection with the clinical practice of intellectual disability (Wehmeyer, 2008; AAIDD, 2010; Buntinx & Schalock, 2010; Schalock, 2011). Like the ICF participation concept, the adaptive behaviour concept is considered as multidimensional, also intended to reflect both perceived and environmental aspects of functioning (Simeonsson, et al., 2001; Gustavsson, 2004; Molin, 2004; Eriksson, 2005; Arvidsson et al., 2008; Maxwell et al., 2012a; Maxwell et al., 2012b). However, there is no consensus neither in how the concept of adaptive behaviour should be defined nor assessed (Arvidsson et al., 2008; Ditterline & Oakland, 2009). Depending on the definition and assessment, adaptive behaviour can be associated with either activity (i.e. ability) and/or participation (i.e. performance) in terms to ICF (Arvidsson et al., 2008; Ditterline & Oakland, 2009). If adaptive behaviour is defined as an adaptive skill, i.e. a matter of ability to perform certain actions, it is more associated with the ICF activity aspect (Gleason & Coster, 2012). If adaptive behaviour is defined as an actual performed behaviour, it is more associated with the participation aspect (Arvidsson et al., 2008; Ditterline & Oakland, 2009; Gleason & Coster, 2012). The main adaptive behaviour assessments, ABAS (Adaptive behaviour assessment scale) (Harrison & Oakland, 2008) and the Vineland scale (Sparrow, Cicchetti & Balla, 2005), operationalize adaptive behaviour as an ability that also has to be performed. According to this operationalization, adaptive behaviour might be considered as a combination of activity and participation, as skills related to performance.

Problems related to an integrative approach to intellectual disability

The quest for an integrative and relative conceptualization of intellectual disability has to some extent led to that the diagnostic criteria have been relativized and somewhat eviscerated (Greenspan et al., 2011; Schalock, 2011). Greenspan et al. (2011) considers that intellectual disability is "defined by bureaucracy-generated artificial and indirect criteria and is not a medical category defined by natural and direct biological criteria" (Greenspan et al., 2011, p. 246). The IQ measure, operationalized by an arbitrary and historically fluctuating cut-off (i.e. 70, or minus two standard deviation units) is alluring in its apparent simplicity. It has, since at least the 1960s, been considered as an insufficient reflector of intellectual impairment (i.e. the intellectual criterion) (Greenspan, 1999; Greenspan et al., 2011; Schalock, 2011). The adaptive criterion was supposed to remedy the IQ

criterion and thus to ensure the clinical relevance of the operationalization of intellectual disability (Greenspan, 1999; Greenspan et al., 2011; Schalock, 2011). However, as the adaptive behaviour criterion has been relativized by psychometric methods, for example cut-offs in terms of standard deviations, this criterion has become quite arbitrary and clinically un-valid (Greenspan et al, 2011). Greenspan (1999; 2006; 2011) discusses the problems with the relative conceptualization of intellectual disability which risks being more a reflector of a political will than of the real problems that it actually means to have intellectual disability. In terms of approaches to disability in general, Greenspan consider that the integrative approach has neither an individual nor an environmental focus (Greenspan 1999; Greenspan et al., 2006; 2011). Greenspan discusses the so called 'supports model', which was derived from a human services philosophy developed in the early1970s in Scandinavia and known as 'the normalization principle' (Nirje, 1985). This trend, aiming at full societal participation and full societal inclusion, implies a view that there are no roles or activities in which people with intellectual disability cannot take part, and this philosophy also implied a potential for people with intellectual disability for success in these roles to be far greater than previously has been appreciated (Greenspan, 1999). According to Greenspan, the problem is neither the belief in the human potential nor the focus on normalization support as such but the subsequent gap between the operationalization and diagnostic practice and the everyday essence of having intellectual disability. A main problem is therefore that policies advocate an integrative operationalization of intellectual disability but the practice is still focusing on the individual, for example diagnostic practices are still focusing on the individual assessment (Greenspan et al., 2011).

Perceived needs

Individuals with a mild intellectual disability are about 80% to 90% of all individuals with intellectual disability and among most of them there is no identifiable physical cause of the disability (Snell et al., 2009). The variation of behavioural features, personalities and lifestyles among individuals with a mild intellectual disability are quite similar to the rest of the human population and certainly similar to individuals with limitations in intellectual function without having an intellectual disability, i.e. an IQ 70-85 (Snell et al., 2009). Regarding everyday functioning, strengths are shown along with limitations; however individuals with a mild intellectual disability perceive significant problems in societal participation (Snell et al., 2009; Thompson et al., 2009; Greenspan et al., 2011; Schalock, 2011; Stuart, 2012). A need can be defined as the absence of some vital necessity for health and well-being and for individuals with intellectual disability a need is rather a long-lasting characteristic than a temporary need for anything specific (Walsh, 2008; Snell et al., 2009; Thompson et al., 2009).

Many adults with a mild intellectual disability strive to manage independently in the community (Snell et al., 2009). Especially after leaving school, the differences between abilities and demands become more complex and then, the risk for adolescents and adults with a mild intellectual disability of getting problems in everyday life increases significantly (Snell et al., 2009; Thompson et al., 2009). Many studies draw attention to these problems in terms of inadequate decision-making and illogical social judgements (Wehmeyer & Boldning, 2001; Greenspan et al., 2006; Snell et al., 2009; Greenspan et al., 2011; Hickson & Khemka, 2013). Difficulty to handle everyday problems is often connected to the limitations in intellectual and adaptive abilities, for example limitations to think abstractly, to understand complex ideas and constructs, and to learn quickly and from experiences (Greenspan et al., 2006; 2011; Hickson & Khemka, 2013). Combinations of limitations and a not-enough-supportive environment make individuals with a mild intellectual disability vulnerable for perceiving participation restrictions in many different life domains such as education, socioeconomic status, employment, housing, health, friendship and social behaviour, family well-being and legal rights (Arvidsson et al., 2008; Walsh, 2008; Snell et al., 2009; Greenspan et al., 2011; Stuart, 2012). Despite the obvious risk of not being able to participate in the society as preferred, an even worse consequence of acting socially inadequate is the risk of being a victim of sexual, economical and/or social abuse (Greenspan et al., 2006; 2011).

However, it is emphasized that not everyone with intellectual disability acts socially inadequate all the time, and that individuals without intellectual disability, at certain circumstances, also have the potential of acting inadequate (Greenspan et al., 2006; 2011; Snell et al., 2009). A main issue in becoming a victim is if the individuals are aware of their own limitations and to know how to compensate gaps between their limitations and the demands of the environment (Greenspan et al., 2006; Walsh, 2008; Snell et al., 2009; Thompson et al., 2009; Greenspan et al., 2011).

Individualized support

Appropriate individualized support, as from clinical services, will enhance functioning in everyday life and reduce the likelihood of acting socially inadequate, and thus the risk for participation restrictions (WHO, 2001; Arvidsson et al., 2008; Snell et al., 2009; Thompson et al., 2009; Buntinx & Schalock, 2010; Arnadottir, Gunnarsdottir, Stenlund & Lundin-Olsson, 2011; Schalock, 2011; Claes et al., 2012a; Stuart, 2012). Conversely, if clinical services being reduced and/or current support being removed, individuals with intellectual disability would not obtain a sufficient adequate functioning in the society, which in turn obviously will affect their health status and general well-being (WHO, 2001;

Simeonsson et al., 2003; Arvidsson et al., 2008; Walsh, 2008; Wehmeyer, 2008; Snell, et al., 2009; Thompson et al., 2009; Schalock, 2011; Claes et al., 2012a).

Even though most individuals with intellectual disability have the legal access to support, they do not necessary perceive the support as available (Eriksson & Granlund, 2004a; 2004b; Walsh, 2008; Snell et al., 2009; Claes et al., 2012a; 2012b; Maxwell et al., 2012a; Stuart, 2012). Individuals with intellectual disability do often perceive needs without actually articulating those needs (Thompson et al., 2009). This might partly be due to problems in being aware of their own limitations as well as difficulties in expressing their needs (Greenspan et al., 2006; Arvidsson et al., 2008; Wehmeyer et al., 2008; Snell et al., 2009; Greenspan et al., 2011; Schalock, 2011). As a consequence, individuals with intellectual disability are often at the mercy of trusting proxy-persons (e.g. family members or support workers) (Rapley Ridgway J & Beyer 1997; Perry & Felce, 2002; Watkins, Espie, Curtice, Mantala, Corp & Foley, 2006; Thompson et al., 2009; Schmidt et al., 2010; Claes et al., 2012a). Therefore, a main issue in clinical services is to develop methods to get accurate knowledge about the perceived needs of the individual (Eriksson & Granlund, 2004a; 2004b; Snell et al., 2009; Claes et al., 2012a; 2012b). It is an essential issue in clinical services to find out how the support should be designed and conducted to match the needs of the individuals (Eriksson & Granlund, 2004a; 2004b; Snell et al., 2009; Thompson et al., 2009; Claes et al., 2012a; 2012b; Stuart, 2012). Hence, there is a methodological challenge to develop assessments that facilitate for the individual to express their own perceived needs and demands without relying on proxy-persons (Arvidsson et al., 2008; Walsh, 2008; Thompson et al., 2009; Eyssen et al., 2011; Claes et al., 2012a).

Aims of the doctoral thesis

The overall aim of this doctoral thesis was to explore an assessment of participation according to the ICF in people with a mild intellectual disability. Regarding this aim, the overall research questions were:
(a) How can participation according to the ICF be assessed?
(b) What is the contribution of a measure of perceived importance to an assessment of participation?
(c) What is the relation between proxy ratings and self-ratings of performance and importance as well as of 'important participation' and 'important participation restrictions'?

The thesis consists of four studies with specific aims which together contribute to the overall research questions.

Specific aims of each study

Study I: The aim was to use empirical data from correlational studies for secondary analyses and to discuss the use of a third qualifier, subjective experience of involvement, as a supplement to the qualifiers of capacity and performance, and to explore activity and participation as endpoints on a continuum of actions.

Study II: The aim was to explore the following questions in Swedish adolescents and adults with a mild intellectual disability: To what extent is there internal consistency in ratings of perceived ability, performance and perceived importance in a preliminary selection of self-reported items rep-resenting different domains in the activity/participation component of the ICF? To what extent do perceived ability, performance and perceived importance correlate?

Study III: The aim was to explore the possibility of assessing participation by combining self-rated measures of the performance of activities with the perceived importance of the same activities, in young adults with a mild intellectual disability. Secondly, the aim was to correlate such assessments of participation with a measure of subjective general well-being.

Study IV: The aim was to compare proxy ratings with self-rated measures of ability, performance and importance as well as measures of important participation and important participation restrictions in adolescents and adults with a mild intellectual disability.

General methodological considerations

According to an integrative approach to disability, the participation concept is considered as an appropriate reflector of an individual's perceived needs and thus relevant to measure in health care services such as rehabilitation practices (Simeonsson et al., 2003; Hemmingsson & Jonsson, 2005; McConachie et al., 2006; Arvidsson et al., 2008; Larsson-Lund & Lexell, 2009; Eyssen, 2011; Küçükdeveci, Tennant, Grimby & Franchignoni, 2011). According to the ICF definition of participation (involvement in life situations), an extensive and multi-faceted operationalized measurement of participation is required.

Psychometric methodologies are often used in psychology and education and the fundament, in for example the selection of items, is a reliance on mathematical techniques such as correlations between items, factor analysis and internal consistency in terms of Cronbach's alpha (Nunally & Bernstein, 1994; Marx, Bombardier, Hogg-Johnson & Wright, 1999; Hwang et al., 2013). The overall aim of a *psychometric approach to assessment* is to develop scales that measure single patient/informant characteristics, and the scales should be considered as 'homogeneous' (Nunally & Bernstein, 1994; Marx et al., 1999; Hwang et al., 2013). With a strictly psychometric approach to assessment a multi-faceted operationalization of participation may be methodologically difficult and maybe also irrelevant but with a clinimetric approach the multidimensionality would rather be seen as an advantage (Nunally & Bernstein, 1994; Marx et al., 1999). The fundament of clinimetric approaches is reliance on the perceptions of informants, patients and clinicians (Feinstein, 1983; Marx et al., 1999). The aim of a *clinimetric approach to assessment* is to measure clinical phenomena that are supposed to include several, not necessarily related, patient characteristics (Feinstein, 1987; Marx et al., 1999. For example, a strategy for choosing the items of a scale can be based on the importance and the severity, rated by the informant/patient, of a large number of possible items (Marx et al., 1999). Thus, such scales are considered as 'heterogeneous' in relation to psychometric standards (Feinstein, 1983; Marx et al., 1999). The main purpose when developing a measurement according to a clinimetric approach is to cover a representative sample of all functions and aspects of the studied phenomenon (Marx et al., 1999, Naglieri, 2009).

Even though the terms reliability and validity mostly might belong to a psychometric approach to assessment, these constructs also have considerable implications for understanding findings by a clinimetric approach (Naglieri, 2009). It might not be the primary aim, but high reliability is desirable because it is for example reflecting the amount of error in the measurement of the construct (Naglieri, 2009). Also, high validity is desirable because it is for example reflecting to which extent the empirical evidence could support a clinical/ecological rele-

vant interpretation of the results (Marx et al., 1999; Naglieri, 2009). Clinimetric and psychometric approaches to assessments should be considered as complementary to each other (Marx et al., 1999). However, if aiming to fulfil all psychometric criteria, an assessment might end up in excluding clinically essential aspects whereas a clinimetric approach is willing to compromise with psychometric criteria in order to obtain an assessment of for example a complex heterogeneous phenomenon such as participation (Wright, Rudicel & Feinstein, 1994; Juniper, Guyatt, Streiner & King, 1997; Marx et al., 1999; Molden & Tøssebro, 2012).

Ethics

The studies were approved by the Regional Ethics Committee of Linköping (dnr: 144-07) and all participants gave informed consent to participate.

Methods of the empirical studies

Study I

Study I was a combined conceptual and empirical article and empirical data from correlational studies were used for secondary analyses. Note that one of the studies used for secondary analyses was study II in this thesis. The analyses in this study were focused on the conceptual roots of the participation construct as indicated by the focus of policy documents, the support for a third qualifier as indicated by correlational data, differences between self-ratings and ratings by others in measuring subjective experience of involvement, and the empirical support for a conceptual distinction between activity and participation in different domains of the activity and participation component.

Study II-IV

Study II, III and IV were similar regarding design. All three studies used tightly structured interviews to assess participation. Study II and III explored self-ratings and study IV explored self-ratings and proxy-ratings. Study II and IV explored ratings of ability, performance and importance, while study III explored ratings of performance and importance solely. Study III and IV also explored measures combining performance and importance (i.e. important participation and important participation restriction). Finally, study III explored general well-being in relation to ability, performance, importance, as well as in relation to important participation and important participation restriction.

Inclusion process and informants, study II-IV

All informants were included within the Swedish municipality of Gävle. Persons who were offered to participate in the studies were at age 16-40 and had any kind of societal service because of intellectual disability such as special school, supported employ and/or supported living. To be included in societal services because of intellectual disability a formal diagnosis is requested, meaning that the person have had a significant low IQ (cut-off is usually set to 70) and before the age of 18 have documented difficulties with adaptive behaviour. This implies that an included person may show a somewhat higher IQ at retest in for example adult age (AAIDD, 2010; Wechsler, 2003; Wechsler, 2010). Also, to be included the person was estimated to understand and be able answer the questions of the participation questionnaire. This estimation was made by teachers or staff persons. All potential participants got oral and written information from the author of this thesis. After that information, and after being recommended to consider their participation, the person decided to say yes or no. Since data was collected consecutively, there is an overlap of informants in study II-IV.

In study II, 106 potential participants were asked to participate in the study and after the inclusion process did 55 (52%) answer yes and were included, 58% men and 42% women. The mean age was 24 and the median age was 20. At the time of the study, the re-tested IQ-score ranged from 56 to 78 with a mean of 68.5 and a median of 68. Sixty per cent of the informants lived with parents and 27% with at least weekly access to professional support. Five per cent lived with a partner. No one lived alone without professional support. Fifty-eight per cent of the informants attended special education and 42 % had special occupational arrangements.

In study III, 122 potential participants were asked to participate in the study and after the inclusion process did 69 (57%) answer yes and were included, 52% men and 48% women. The mean age was 24.8 and the median age was 22. At the time of this study, the re-tested IQ ranged from 56 to 78 with a mean of 67.5 and a median of 67. Fifty-seven per cent of the informants lived with parents, 19% with daily professional support, and 16% with approximately weekly professional support. Three per cent lived with a partner. No one lived alone without professional support. Forty-six per cent of the informants attended special education and 54 % had special occupational arrangements.

In study IV, 40 participants with a mild intellectual disability were included, 55% men and 45% women. The age ranged from 16-40, the mean age was 23.6 and the median age was 21. At the time of the study, the re-tested IQ ranged from 56 to 79 with a mean of 69.9 and a median of 70. Fifty-five per cent of the participants lived with parents, 17.5% with daily professional support, 17.5% with approximately weekly professional support, and 7.5% lived with a partner. One person (3%) lived alone without any reported professional support. Fifty per cent of the participants attended special education and 50 % had special occupational arrangements. After the interviews, 40 proxy-persons were included. The person with intellectual disability was asked to choose a proxy-person that, on his/her behalf, should conduct the same interview. The person with intellectual disability was asked to choose someone who knows him/her well and that he/she wanted to answer questions about him/her. Among the proxy-persons, 47.5% was a professional person (staff or teacher), 30% was a relative, 12.5% was a partner, and 10% was a close friend.

Materials and data collection, study II-IV

The participation questionnaire

In study II-IV, the self-ratings and proxy-ratings of ability, performance and importance were conducted as a tightly structured interview/verbal survey and the questionnaire included 68 items representing a selection of categories from

each of the nine ICF domains of the activity/participation component: 1) Learning and applying knowledge (6 items), 2) General tasks and demands (5 items), 3) Communication (8 items), 4) Mobility (6 items), 5) Self-care (8 items), 6) Domestic life (8 items), 7) Interpersonal interactions and relationships (11 items), 8) Major life areas (5 items), 9) Community, social and civic life (11 items) (WHO, 2001).

Based on the ICF list of activity/participation items, a tentative selection of items from all nine life domains was made. The items were discussed in a group of researchers with the ICF and/or intellectual disability as a research field. Also, the items were discussed in a group of clinicians at a rehabilitation service centre for people with intellectual disability. The intention was that the selected ICF items should be relevant to individuals with a mild intellectual disability (Arvidsson et al., 2008; AAIDD, 2010). Thus, the selection of items should pay attention to issues used in the Adaptive Behavior Assessment System-II (Harrison & Oakland, 2008), i.e. the selected items should reflect general cognitive/conceptual issues as well as practical and social situations and functioning. The intention was also to pay attention to discussions during clinical implementations of the ICF model and the development of the ICF Universal Code sets (Ibragimova, Lillvist, Pless & Granlund, 2007; Ibragimova, Granlund & Björck-Åkesson, 2009; Pless et al., 2009; Adolfsson, Granlund, Björck-Åkesson, Ibragimova & Pless, 2010; Ellingsen, 2011). The final questionnaire was piloted by interviewing and getting feed-back from two individuals with a mild intellectual disability. The piloting led to some minor adjustments with respect to clarity and understanding of some items.

Measures of ability, performance and importance

All the informants in study II-IV and all the proxy-persons in study IV were face-to-face interviewed by the author of this thesis, a clinical psychologist with experience from assessing and rehabilitation with respect to intellectual disability. The questionnaire was conducted according to the order of appearance in the ICF manual (WHO, 2001). In order to explore each item regarding the aspects of perceived ability, performance, and perceived importance, the interviewer asked, related to the present situation, about the following verbal alternatives and scored these as a three-grade Likert scale:

- *Perceived ability* – I can do this fully without any help or support (2), I can do it to some extent (1), I cannot do this (0).
- *Performance* – I do this often (2), I sometimes or seldom (1), I never do this (0).

- *Perceived importance* – this is very important to me (2), this is somewhat important (1), this is not important at all (0).

The three-grade Likert scale was chosen with respect to recommendation for people with a mild intellectual disability (Hartley & MacLean, 2008; Claes et al., 2012a). Regarding each item, the order of stating questions about ability, performance, and importance respectively was allowed to vary depending on the order of spontaneous answers given by the informants. There was time for reflection and reasoning in order to secure that the informants understood the items and the distinctions between the mentioned aspects. All in all, the questionnaire took 60-70 minutes to complete.

General subjective well-being (study III)

Immediately after the participation questionnaire the informant was asked about their perception of general well-being and they were told to take the whole life-situation into account. The rating was conducted by a single-item question (Andrews & Withey, 1976; Pavot & Diener, 1993; Diener, Lucas & Oisho, 2002; Diener, 2009; Stiel, Kues, Krumm, Radbruch & Elsner, 2011; Paiva & Paiva, 2011). The question of general well-being was: "Taking all life areas into account, how do you feel about your life?" (Andrews & Withey, 1976; Pavot & Diener, 1993; Diener, 2009). The informants were asked to rate on a 5 grade scale with the following verbal alternatives: 1= very bad, it could not possibly be worse, 2= between the worst and the middle, 3= in the middle, 4= between the middle and the best, 5= very good, it could not possibly be better. This measurement was piloted for people with intellectual disability in clinical practice.

Intelligence quaint (IQ)

In study II-IV, full scale IQ for each informant was assessed with the Wechsler Adult Intelligence Scale (Wechsler, 2003; Wechsler, 2010).

Data exploration, study III and IV

Dichotomization of data

Due to the proportion of the overall frequencies of 0,1,2-ratings of performance, importance (study III and IV) and ability (study IV) data analyses were based on dichotomized data. The ratings scored (0) and (1) were combined and labelled "low" and the ratings scored (2) were labelled "high". Hence, the measures of performance and importance (study III and IV) and ability (study IV) were based on the frequencies of "high"-ratings. Also, the measures of 'important participation' and 'important participation restriction' (study III and IV) were based on dichotomized data.

Measures of ability, performance and importance

In study III, the correlated measures of high performance and high perceived importance were based on the sums of high-rated items (see dichotomization of data above), informant by informant for performance and perceived importance respectively. The correlated measures of low performance were based on the sums of low-rated items, informant by informant for performance. In study IV the correlated measure of ability were based on the frequencies of high-rated items. Since there were 68 items, the hypothetical span of these measures was 0-68.

Measures of important participation and important participation restriction

In study III and IV, two measures, 'Important participation' and 'Important participation restriction', were derived from a combination of performance and importance. The measure of performance in combination with high importance, called 'important participation', was based on the sums, informant by informant, of items rated high of both performance and importance. The measure of low performance in combination with high importance, called 'important participation restriction', was based on the sums, informant by informant, of items rated low in performance in combination with high of importance. Since there were 68 items, also for these two combined measures the hypothetical span was 0-68.

Data analysis, study II-IV

Internal consistency

Cronbach's alpha was used to examine the internal consistency of ability, performance and importance. In study II, the internal consistency was examined for self-ratings of the total scales of 68 items and also for each domain. In study III, internal consistency was examined for self-ratings of the total scales of performance and importance. In study IV, internal consistency was examined for self-ratings and proxy-ratings of the total scales of ability, performance and importance.

Correlations

Spearman rank correlation was used to examine correlations. Study II, examines correlations – with respect to each item – between perceived ability, performance, and perceived importance. Study III examines correlations – on total scales – between measures of performance, importance, measures performance in combination with importance, and general well-being. Study IV examines correlations between self-ratings and proxy-ratings of ability, performance, im-

portance, as well as of 'important participation' and 'important participation restriction'.

Ranking lists of items

Study III examines different ranking lists of the 68 items in the structured interview guide. The ranking lists of high performance and high perceived importance were based on the sums of informants that, item by item, rated the item high. The ranking list of low performance was based on the sums of informants that, item by item, rated the item low. The ranking list of 'important participation' was based on the sums of informants that, item by item, rated the item high of both performance and importance. The ranking list of 'important participation restriction' was based on the sums of informants that, item by item, rated the item low of performance and high importance. The results were presented as percentages of the number of informants.

Differences between self-ratings and proxy-ratings

In study IV, Wilcoxon Signed Ranks Test was used to examine differences between scores of self-ratings and proxy-ratings of ability, performance, importance, as well as of 'important participation' and 'important participation restriction'.

Summary of empirical studies

Study I. Differentiating Activity and Participation of Children and Youth with Disability in Sweden - A Third Qualifier in ICF-CY

Aim

The aim was to explore the use of a third qualifier, subjective experience of involvement, as a supplement to the qualifiers of capacity (i.e. ability) and performance, to explore activity and participation as endpoints on a continuum of actions.

Method

Empirical data from correlational studies were used for secondary analyses. The analyses were focused on the conceptual roots of the participation construct as indicated by the focus of policy documents, the support for a third qualifier as indicated by correlational data, differences between self-ratings and ratings by others in measuring subjective experience of involvement, and the empirical support for a distinction between activity and participation in different domains of the activity and participation component.

Results

Findings from analyses of policy documents indicate that participation seems to have two conceptual roots, one sociologic and one psychological. However, the sociological root, which mainly focuses participation as availability, accessibility and opportunities were overrepresented. Findings regarding statistical analyses of 68 activity items from the ICF activity/participation component showed a mean correlations coefficient of 0.47 between self-ratings the ability and performance, 0.59 between performance and subjective experience of involvement, and 0.28 between ability and performance. The later domains in the activity/participation (domain 5-9) component showed better fit with measures of experienced involvement than the first domains (1-4) did. Findings regarding correlations between students' self-ratings of participation in school activities and teachers' ratings of the same students' participation in school activities using the same questionnaire showed low correlation values. These results indicate that self-ratings of participation provide information not obtained through ratings by others.

Conclusion

The results from secondary analyses provide preliminary support for the use of a third qualifier measuring subjective experience of involvement to facilitate the

distinction between ability and performance in the ICF activity/participation component.

Study II. International Classification of Functioning, Disability and Health categories explored for self-rated participation in Swedish adolescents and adults with a mild Intellectual disability.

Aim

The aim of the study was to explore the following questions in Swedish adolescents and adults with a mild intellectual disability: To what extent is there internal consistency in ratings of perceived ability, performance and perceived importance in a preliminary selection of self-reported items representing different domains in the activity/participation component of the ICF? To what extent do perceived ability, performance and perceived importance correlate?

Method

This was a structured interview study with 55 Swedish adolescents and adults with a mild intellectual disability. Questions about perceived ability, performance and perceived importance were asked on the basis of a 3-grade Likert-scale regarding each of 68 items representing the nine ICF domains of activity/participation.

Results

Self-ratings about perceived ability, performance and perceived importance of the 68 activity items representing the nine ICF domains of activity/participation were analysed and findings regarding internal consistency (Cronbach's alpha value for the whole scale of 68 items) for *perceived ability* was 0.95, while the alpha value for each domain varied between 0.57 and 0.85. For *performance*, the alpha value was 0.86 for the whole scale and varied between 0.27 and 0.66 for each domain. The low alpha values (< 0.5) represented the domains of learning and applying knowledge, communication, mobility, and major life areas. For *perceived importance*, the alpha value for the whole scale was 0.84, while it varied between 0.27 and 0.68 for each domain. The low alpha values represented the domains of learning and applying knowledge, communication, mobility, and self-care.

Findings regarding correlations, item by item, showed that 72% of the correlations between *performance and perceived importance* were high with a mean correlation coefficient among all the 68 items of 0.59 (median 0.64): for example, within the domain of learning and applying knowledge each item showed high correlations between these aspects. Within the domain of mobility each item showed high correlations except driving a car. Within the domain of domestic life each item showed high correlations, except residing as preferred. In contrast, there were no high correlations between these aspects within the domain of general tasks and demands. The results regarding correlations, item by item,

showed that 41% of the items high correlations (0.5 or higher) between *perceived ability and performance* were high, with a mean correlation coefficient among all 68 items of 0.47 (median 0.45): for example, within the domain of domestic life each item showed high correlations, except residing as preferred. In contrast, there were no high correlations between these aspects within the domain of community, social and civic life. Only 12% of the items showed high correlations between *perceived ability and perceived importance*, with a mean correlation coefficient among all 68 items of 0.28 (median 0.25): there were no high correlations within any of the first four domains, and within each of the domains 5–9 there were only one or two items with high correlations between these aspects.

Conclusion

A preliminary selection of items was used to explore how self-reported assessments of participation could be based on ICF categories. Within each specific domain, the Cronbach's alpha values were high or reasonably high with respect to the ability aspect, while the values, on average, were below 0.5 with respect to performance and the importance aspect. It indicates that measures of performance and perceived importance may have to be based primarily on their estimated clinical relevance for describing aspects of the participation concept rather than on their psychometric properties. The high correlations between perceived importance and performance may indicate that respondents conceive performance and importance as closely related, but somewhat different, aspects of participation. The varied correlations between perceived ability and performance indicate that different items within domains, as well as different domains, are to a varying extent influenced by the perceived aspect of involvement as well as environmental factors. The last domains (5-9) seem to be more influenced by the perceived aspect than the first (1-4). With a clinimetric approach, relevant parts of the studied items and domains may be used to investigate factors related to different patterns and levels of participation, and to evaluate interventions related to participation.

Study III. Important aspects of participation and participation restrictions in people with a mild intellectual disability

Aim

The aim of this study was to explore the possibility of assessing participation by combining self-rated measures of the performance of activities with the perceived importance of the same activities, in young adults with a mild intellectual disability. Secondly, the study aimed to correlate such assessments of participation with a measure of subjective general well-being.

Method

This was a structured interview study with 69 Swedish adolescents and adults with a mild intellectual disability. Questions about performance and perceived importance were asked on the basis of a 3-grade Likert-scale regarding each of 68 items representing the nine ICF domains of participation. The 68 items were ranked on the basis on perceived importance, performance and on the basis on the combined measures. Also, measures of performance and performance in combination with importance were related to self-rated general well-being.

Results

Regarding analyses of measures considered as participation, findings showed that 30 of the 68 activity items were rated high in performance (i.e. often performed) by 50% or more of the informants, and the ranking list of items highlighted domain 5) self-care, domain 2) general tasks and demands, and to some extent 6) domestic life. Twenty-eight items were rated high of 'important participation' (i.e. often performed and perceived important) by 50% or more of the informants, and this ranking list largely highlighted the same items as the ranking of high performance solely.

Regarding analyses of measures considered as participation restriction, findings showed that 19 of the 68 items were rated low in performance (not or seldom performed) by 50 % or more of the informants and the ranking list of low performance highlighted domain 9) community, social and civic life, and domain 7) interpersonal interactions and relationships. Eighteen items were rated low of 'important participation restriction' (i.e. not or seldom performed even though the item was perceived important to perform) by 25 % or more of the informants. To some extent, this ranking also highlighted items, from domain 9) community, social and civic life, and from domain 7) interpersonal interactions and relationships, however not the same items that the ranking of low performance solely highlighted.

Findings from correlation analyses taking the whole scale of 68 items into account, showed a significant positive correlations between general well-being and

self-rated high performance (r=0.56) and between general well-being and 'important participation' (r=0.56). There were significant negative correlations between general well-being and self-rated low performance (r=-0.56) and between general well-being and 'important participation restriction' (r=-0.55). No correlation was found between general well-being and perceived importance (r=0.08, p=0.50). Between high performance and high importance, there was a significant correlation (r=0.52).

Conclusion

The results confirm the relevance of our selection of 68 items from the ICF domains of participation. The findings in the study indicate that a measure based on performance solely might be sufficient to assess participation and participation restriction, at a group level. However, for clinical contexts when supporting single individuals with intellectual disability, with the aim to understand specific needs regarding participation, a measure capturing the subjective awareness of the relation between the actual frequency and perceived importance of involvement is required.

Study IV. The relation between proxy-ratings and self-ratings of participation in people with a mild intellectual disability

Aim

The aim of this study was to compare proxy ratings with self-rated measures of ability, performance and importance as well as measures of important participation and important participation restrictions in adolescents and adults with a mild intellectual disability.

Method

This was a structured interview study with 40 Swedish adolescents and adults with a mild intellectual disability and 40 paired proxy-persons. The same questions about ability, performance and importance were asked – to both the person with intellectual disability and to the proxy-person – on the basis of a 3-grade Likert-scale regarding each of 68 items representing the nine ICF domains of participation. Measures of ability, performance and importance, as well as measures of performance in combination with importance, were compared by paired samples of the person with intellectual disability and the proxy-person.

Results

Both self-ratings and proxy-ratings about ability, performance and importance of the 68 activity were analysed regarding internal consistency in terms of Cronbach's alpha. Findings showed similar patterns and levels of alpha values when self-ratings and proxy-ratings were compared. The alpha values were, for ability: 0.95 for self-ratings and 0.91 for proxy- ratings, for performance: 0.87 for self- ratings and 0.86 for proxy-ratings, and for importance: 0.77 for self-ratings and 0.80 for proxy-ratings.

Findings from correlation analyses, taking the whole scale of 68 items into account, between self-ratings and proxy-ratings showed a significant positive correlations regarding ability ($r=0.62$) and performance ($r=0.63$), and regarding the combined measures important participation ($r=0.65$) and important participation restriction ($r=0.53$). There was no significant correlation regarding importance solely ($r=0.30$). Important participation= high performance in combination with high perceived importance. Important participation restriction= low performance in combination with high perceived importance.

Mean scores of self-ratings were compared to mean scores of proxy-ratings. The results showed that the score of self-rated importance and self-rated important participation restriction was higher than the same proxy-rated measure. The persons with intellectual disability rated approximately 45 items as important compared to approximately 41 items rated by the proxy-persons, and the persons with intellectual disability rated approximately 14 items as importantly

restricted compared to approximately 11 items rated by the proxy-persons. Both these paired sampled differences were significant and strong (0.010 for both). Also, the analyses of paired samples of self-ratings and proxy-ratings for mean score levels of overall ability showed that approximately 52 items were rated high by persons with intellectual disability and approximately 48 items were rated high by proxy-persons. This paired sample was significant but weak (0.049). The mean scores of performance and important participation were almost identical, for performance: 31.7 and 32.0 for self-ratings and proxy-ratings respectively, and for important participation 30.7 and 30.4 for self-ratings and proxy-ratings respectively. These differences were not significant.

Conclusion

The main results conclude that self-ratings and proxy-ratings are correlated but that there are differences in levels of ratings of ability and perceived participation restriction, and that self-rated data is preferable provided that such data is available. The study did not evaluate the relation between the self-ratings and proxy-ratings in terms of right or wrong, however indicated that awareness about the similarities and differences between the perceived ability and participation of the person with intellectual disability him-/herself and the perception of a proxy-person is essential in clinical practice.

Main results

The overall aim of this doctoral thesis was to explore an assessment of participation according to the ICF in people with a mild intellectual. Regarding this aim, the overall research questions were: How can participation according to the ICF be assessed? What is the contribution of a measure of perceived importance to an assessment of participation? What is the relation between proxy ratings and self-ratings of performance and importance as well as of 'important participation' and 'important participation restrictions'? Results from all four studies of this thesis do altogether contribute to answer these overall research questions, and there is an obvious overlap in to what degree the four studies contribute.

How can participation according to the ICF be assessed?

The question of how participation could be conceptualized and assessed was explored in all four studies of this thesis. Results from the conceptual exploration in study I, which indicated that participation has at least two conceptual roots, one sociological/environmental and one psychological/individual, implied that participation should be multidimensional assessed. Results from study I also indicated that a third qualifier, a perceived aspect of the involvement is both conceptually and clinically relevant. However, the analyses of Swedish and Scottish education policy documents indicated that participation is frequently conceptualized as performance rather than as the subjective experience of involvement. In study I and II, correlational patterns between items regarding ability, performance, and perceived importance (i.e. subjective experience of involvement) showed relatively high correlations between ability and performance, and between performance and perceived importance. For correlations between ability and performance, the findings indicated that the items from the earlier domains (1-4) were more frequently high related to each other. For correlations between performance and perceived importance, the findings indicated that items from the later domains (5-9) were more frequently high related to each other.

Study II explored the 68 tentatively selected activity items from the ICF list of life situations in the activity/participation component, i.e. *the participation questionnaire*, and the results showed excellent internal consistency in terms of Cronbach's alpha for the whole scale for ability (alpha=0.95), performance (alpha=0.87) and perceived importance (alpha=0.84). All through, the internal consistency was best for perceived ability and less good for perceived importance. For ability, the internal consistency for specific domains was acceptable (mean alpha=0.72). However, the internal consistency for specific domains was low for both performance (mean alpha=0.51) and importance (mean alpha=0.50).

Results from study III indicated relevance in operationalizing participation as either actual performance or as actual performance in combination with perceived importance. Study III found significant positive correlations between general well-being and self-rated performance and between general well-being and high performance in combination with high importance ('important participation'). Study III also found significant negative correlations between general well-being and measures of participation restrictions, i.e. self-rated low performance and low performance in combination with high importance ('important participation restriction').

In study IV, analyses of the relation between self-ratings and proxy-ratings and analyses of internal consistency regarding showed differences regarding perceived importance and important participation restrictions. Thus, if participation should be measured as a combination of actual performance and perceived importance, the result indicated that self-ratings preferable. However, if participation is measured by actual performance solely, study IV showed high similarities between self-ratings and proxy-ratings.

Altogether, findings of this thesis show that people with intellectual disability handle perceived ability, performance and perceived importance as somewhat similar but separate concepts. The results also indicate that participation may be measured as performance solely but also that a perceived aspect of the involvement (i.e. perceived importance) is both conceptually and clinically relevant to combine with actual performance in a measure of participation. Differences between self-ratings and proxy-ratings indicate that a participation measure including a perceived aspect of performance might better be assessed by self-ratings.

What is the contribution of a measure of perceived importance to an assessment of participation?

The need for a subjective aspect of involvement was investigated in study I. Findings considered the individual perception of involvement as one essential aspect of the participation concept.

The results in study III showed no differences in correlation values between participation and subjective general well-being whether participation was measured by solely performance or performance in combination with perceived importance. Study IV explored correlations and differences in scores of participation measures between self-ratings and proxy-ratings. The results showed corresponding correlations values and rating levels of performance but significant differences regarding perceived importance and important participation restrictions.

Study III also compared ranking lists of the 68 selected items regarding measures of participation. The list based on performance solely and the lists combining performance with perceived importance highlighted different items, especially the list of low performance and the list of 'important participation restriction'.

Altogether findings from study III and IV implied that ratings of perceived importance in combination with actual performance appear to add information to a measure of participation in comparison to the information of performance solely. This finding is more obvious regarding participation restrictions.

What is the relation between proxy ratings and self-ratings of performance and importance as well as of 'important participation' and 'important participation restrictions'?

Study II explored the correlations relation between ability, performance and importance. The relation was explored item by items (the participation questionnaire) and the results showed that 72% of the items for performance vs. perceived importance were highly correlated[1], that 41% of the items for ability vs. performance were highly correlated, and that 12% of the items for perceived ability vs. perceived importance were highly correlated. The findings from study II showed that individuals with a mild intellectual disability were able to discriminate between the ability on one hand, and performance and importance on the other. The result supports that ability and importance that participation can be reliable assessed by self-ratings in the target group.

Study IV specifically aimed to investigate the association between self-ratings and proxy-ratings. The study showed similar results for internal consistency as in study II which supports finding from study II regarding the high reliability of the explored assessment (the participation questionnaire). Study IV explored the correlation between self-ratings and proxy-ratings for ability, performance and importance, and for measures combining performance and importance. The correlations between self-ratings and proxy-ratings were significant positive correlations for ability (r=0.62), for performance (r=0.63), and for 'important participation' (r=0.65) and 'important participation restriction' (r=0.53). No significant correlation was found for importance solely. Study IV also explored differences in mean scores of participation measures between self-ratings and proxy-ratings. The results showed that the score of self-rated importance and self-rated important participation restriction was higher than the same proxy-rated measure. The persons with intellectual disability rated approximately 45 items as important compared to approximately 41 items rated by the proxy-persons, and the

[1] A correlation coefficient > 0.5 were considered as high.

persons with intellectual disability rated approximately 14 items as importantly restricted compared to approximately 11 items rated by the proxy-persons. Both these paired sampled differences were significant and strong. Also, the analyses of paired samples of self-ratings and proxy-ratings for mean score levels of overall ability showed that approximately 52 items were rated high by persons with intellectual disability and approximately 48 items were rated high by proxy-persons. This paired sample was significant but weak. The mean scores of performance and important participation were almost identical, for performance: 31.7 and 32.0 for self-ratings and proxy-ratings respectively, and for important participation 30.7 and 30.4 for self-ratings and proxy-ratings respectively. These differences were not significant.

Altogether, findings from study II and IV suggest that if participation is measured by performance solely, self-ratings as proxy-ratings might be interchangeable. However, if a perceived aspect of performance is included in a measure of participation, or whenever the knowledge about the perceived aspect of the individual is essential, self-ratings seems preferable.

Methodological discussion

Participants

In study II, 55 of 106 (52%) potential individuals decided to participate and in study III the corresponding figures were 69 of 122 (57%). These rather low rates of 'yes' compared to 'no' might have biased the results of this thesis. The validity of the findings to be representative for people with a mild intellectual disability in general may be questionable.

To be included in the studies in the first place, the person had to be estimated to understand and be able to answer the questions of the participation questionnaire. This estimation was made by a teacher or a staff person. After the estimation all potential participants got oral and written information from the author of this thesis. After the information, the person was recommended to consider their participation, preferably with a for example a relative, before they decided whether to participate or not. This long inclusion process was basically done due to ethical reasons, the person had to be provided proper time to think about whether participating or not. However, the information could have been clearer and more concrete, for example by demonstrating the participation questionnaire by asking the teacher some of the questions.

The person didn't have to give any reason to why he och she didn't want to participate. Among the spontaneously given reason, however, doubts for the length of the interview and "loss of desire" were frequently most reported. One possible consequence of this might have been an overrepresentation of persons with generally high self-confidence and high well-being. This interpretation is somewhat supported by the rather high values regarding subjective general well-being (study III); a mean of 3.7 and median of 4 in a scale of 1-5. It can be assumed that this 'well-being-bias' has affected the general levels of participation and participation restrictions. Thus, not at least from a clinical point-of-view, it is essential to explore the assessment of participation and participation restrictions also in persons with a lower general well-being.

Doubts for being IQ-tested were also told as a reason for not taking part in the studies and a possible consequence of this might have been an overrepresentation of persons with rather high cognitive functioning. The comparatively high IQ scores of the participants compared to the assumed IQ-score for the group of mild intellectual disability (55-70) support such notion. In study II, the IQ-range was 56-78 with a mean of 68.5 and a median of 68, in study III the range was 56-78 with a mean of 67.5 and a median of 67, and in study IV the range was 56-79 with a mean of 69.9 and a median of 70. Of course, no data of IQ is available for the persons that didn't want to participate. However, analyses of the relation between IQ-scores and measures of participation (performance and performance

combined with importance) showed correlations of 0.09-0.10 (un-published data). Thus, this 'IQ-bias' might not have affected the aim to explore a possible assessment of participation in the target group to any significant extent. However, it is essential to further explore assessment of participation and participation restrictions in persons with different levels of cognitive functioning.

Measures

This thesis explored assessment of participation according to the ICF in people in the age of 16-40 with a mild intellectual disability. Participation was explored by measures of both performance and performance in combination with perceived importance. Findings in study I support the need for a perceived importance (individually perceived aspect of involvement) qualifier. However, study I was partly originated based on empirical data primarily collected for other purposes. The reliance on these data and the secondary analyses implies that the findings from study I can only be seen as preliminary support for the conclusions drawn. Hence, the need for more empirical data from primary analyses is described in this first study of this thesis.

The selection of items

In study II-IV, a selection of 68 items was used to explore an assessment of participation. The selection started from the ICF list of activity/participation items and a tentative selection of items from all nine life domains was made. The items were discussed in a research group with ICF and/or intellectual disability as a research interest. The items were also discussed in a group of clinician at a rehabilitation service centre for intellectual disability. The intention was that the selected ICF items should be relevant for people with a mild intellectual disability (Arvidsson et al., 2008; AAIDD, 2010). During the selection of items attention was also paid to items used in the Adaptive Behavior Assessment System-II regarding cognitive/conceptual, as well as practical and social situations and functioning (Harrison & Oakland, 2008). Attention was also paid to discussions during clinical implementations of the ICF model and the development of the ICF Universal Code sets (Ibragimova et al., 2007; Ibragimova et al., 2009; Pless et al., 2009; Adolfsson et al., 2010; Ellingsen, 2011). Finally, the questionnaire was piloted by interviewing and getting feed-back from two individuals with a mild intellectual disability.

Of course, this selection of items can always be questioned and different approaches would have been possible. For example, the selection could have been based on qualitative open interviews or focus groups (Sverker et al., in press). However, due to the well-known difficulties in many individuals with intellectual disability to express themselves in a nuanced manner, such qualitative methods would have been questionable (Greenspan et al., 2006; Arvidsson et al.,

2008; Wehmeyer et al., 2008; Snell et al., 2009; Thompson et al., 2009; Greenspan et al., 2011; Schalock, 2011; Hickson & Khemka, 2013).

The selection of items is also made from practical reasons. Theoretically, it might have been possible to explore all activity items at, for example, the second level of the ICF activity/participation component (approximately 120 items). However, such list of items was considered as too extensive. Hence, to study participation empirically it was necessary to make a selection of items from the extensive lists of the nine domains (WHO, 2001). Still, the selection is somewhat tentative, but it may be regarded as a strength that the selection of items is based on the ICF and that the items were discussed in relevant clinical practices. The finding in study III, that 52 of the 68 activity/participation items were perceived to be important by 50 % or more of the informants, supports the relevance of the selection. However, to confirm this relevance, both for people with intellectual disability and other clinical groups, further studies are needed.

Study II explored internal consistency in terms of Cronbach's alpha and results for the 68 selected items as a scale showed an alpha of 0.95 for perceived ability, 0.87 for performance and 0.84 for perceived importance. Findings in study IV showed basically the same values. Results from analyses of each domain showed acceptable internal consistency for ability (mean alpha=0.72). However, for performance and perceived importance, the internal consistency for specific domains was low (mean alpha=0.51 and 0.50 respectively). High values indicate that the included items may be regarded as one dimension of measurement, in the sense that although the items differ from each other they reflect a common construct. The value is dependent on both the homogeneity and the number of items. Regarding each specific domain, the Cronbach´s alpha values were reasonably high with respect to the ability aspect, while the values were low regarding some domains with respect to the performance aspect and the importance aspect.

This finding might be taken as an argument for to handle activity and participation as separate lists (WHO, 2001; Badley, 2008; Coster & Khetani, 2008). It might also been taken as an indicator for that the list of ICF activity items are developed from an activity point-of-view (activities that people have the ability to perform or not) rather than from a participation point-of-view (activities that people actually do and/or actually perceive important to perform at all) (Klang, 2012; Maxwell, 2012c). The findings also indicate that ratings of performance are always made within an assumed situation, with some simultaneous subjective experience, and people will experience contexts differently and thus perceive them differently. Therefore it is unlikely that acts representing the same category in terms of latent constructs based on ability will have inter-correlations in terms of performance and subjective experiences.

These findings can also be considered as consistent with that a bipartite social models of disability do not recognize a decontextualized individual perspective of participation or a depersonalized environmental perspective but that an execution of a task is always in a context (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006; Sverker et al., in press). Thus, the ratings of ability, as well as the ratings of performance and perceived importance are considered as rated in a context. In a context/life situation, the relation between ability and performance can be considered as a continuum with ability at the first end-point, via actual performance, to perceived involvement at the other end-point (Simeonsson, et al., 2001; Gustavsson, 2004; Molin, 2004; Arvidsson et al, 2008; Maxwell, 2012c). This continuum of aspects can be studied empirically without any a priori distinction between activity and participation and the term activity can be used just to denote the ICF list of things that people may do (Nordenfelt, 2006; Sverker et al., in press). Findings from study II, where the results showed higher correlations between ability and performance, and between performance and perceived importance, but low correlations between perceived ability and perceived importance, somewhat support this considered continuum.

To measure the aspects of performance and perceived importance it is important to develop measures using an approach which does not just rely on psychometrics but rather on clinimetric principals (Feinstein, 1983; Whiteneck & Dijkers, 2009). According to a clinimetric approach, each item used in an assessment is assumed as a less-than-perfect illustration of an underlying construct without any hierarchical relation to other items representing the same construct (Feinstein, 1983; Whiteneck & Dijkers, 2009). With a clinimetric approach, that also considers clinical relevance and relations to relevant conceptual models, the 68 items explored in this thesis are designed to measure different aspects (ability, performance, and importance) of a phenomenon (participation). The three aspects which might represent the same construct because they reflect a life situation even if they only have low to moderate inter-correlations in general measurements. However, to really confirm that ability, performance, and importance reflects the same underling concept, further studies have to be implemented.

In a traditional psychometric perspective, the importance of high alpha coefficients is often emphasized. Also, there is often an aim to reduce the number of items that correlate strongly with each other (Marx et al., 1999; Katz, Morris & Yelin, 2006; Hwang et al., 2013), which may be possible with respect to findings of the ability aspect. But with respect to the findings of the participation aspects (performance and importance) it seems relevant to pay attention to clinimetric aspects, such as the relation to an integrative model of disability and contextual factors, and sensitivity to variation and change regarding a broad range of issues that may be clinically important according to the perspective of an individual

person with intellectual disability (Feinstein, 1983; Marx et al., 1999; Fava, Tomba, & Sonino, 2012). With consideration to this, each of the resulting alpha coefficients corresponding to the different aspect of participation may be regarded as acceptable in a clinical perspective. Also, findings from study III, that 52 of the 68 activity/participation items were perceived to be important by 50 % or more of the informants, support the clinical relevance of the items, at least for the studied group. However, further research in people with intellectual disability is needed to further establish the findings.

The three-grade scale

The three-grade Likert scale was chosen with respect to recommendations for people with a mild intellectual disability (Hartley & MacLean, 2008; Claes et al., 2012a). Of course, there could have been some valuable nuances missing by using the 3-grade scale. Moreover, valuable nuances could have been missing because of the dichotomization of data into high/low ratings. However, the main findings of this thesis, that participation and participation restrictions can be assessed by combining performance and perceived importance, and the contribution of the perceived aspect of participation, would not be questioned because of this. Instead, if more nuanced response alternatives would have been used the findings might have been even clearer.

Correlations to well-being

Study III explores correlation between subjective general well-being and measures of participation and participation restrictions. There were significant positive correlations between general well-being and self-rated high performance (r=0.56) and between general well-being and 'important participation' (r=0.56), and there were significant negative correlations between general well-being and self-rated low performance (r=-0.56) and between general well-being and 'important participation restriction' (r=-0.55). The correlation values indicate that about 30% (approximately 0.55^2) of the variation in the participation measures explored in study III are (at least statistically) related to subjective general well-being. . The correlations values as such must of course be interpreted carefully and the finding may be regarded as a rough client-oriented validation of the measures of participation. From a clinical point-of-view, the correlation values as such might not be the most important aspect to pay attention to. It might be more interesting that there is a significant correlation at all, and if the correlation sign is positive or negative. Still, the findings from the explored measures in study III indicate that 70% of "something else", at least statistically, is related to subjective well-being. Hence, the relation between participation and general well-being has to be further studied.

General discussion

Assessing participation

The aim of this doctoral thesis was to explore self-assessments of participation according to the ICF in people with a mild intellectual disability, and also to explore the contribution of a perceived aspect of involvement to such assessments.

The ICF activity and participation component is developed in purpose to reflect general health and everyday functioning (WHO, 2001). The activity aspect is supposed to reflect the capacity to perform a certain activity in an assumed standardized context while participation is supposed to reflect the actual involvement in different life situations. The ICF doesn't provide any straightforward method to assess participation; however the actual performance is suggested as an appropriate qualifier. The ICF provides nine life domains in which the capacity and performance can be described and the included choice of activities seems to be guided by an underlying idea that these activities are generally good and healthy for people to perform (study III).

The relation and difference between activity and participation is problematic, especially if activity is used to denote performance in a decontextualized individual perspective, an option that is offered in the ICF (WHO, 2001; Badley, 2008). According to the theoretical perspectives of bipartite social models of disability, all activities are performed in a context and the rationale of the mentioned option may thus be questioned (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006; Shakespeare, 2006; Sverker et al, in press). One main argument is that also tasks and actions that are considered as non-complex or 'simple' can be a part of other life situations that might be involved in larger and/or longer-term life plans (Nordenfelt, 2003; 2006). If all performances of human activities are considered as contextual, they only have to be theoretically separated from body functions (Nordenfelt, 2006; Sverker et al, in press). Instead of using the term capacity to denote what people are able to perform, the term *ability* may be used, a usage that seems to tally with how it is used when capacity is defined in the ICF. Then, the term *performance* can be used just to denote what a person actually does in a context and the term activity just to describe items of the whole activity/participation list of different things that people may do, all in accordance with social models of disability and with option 4 of annex 3 of the ICF (WHO, 2001; Nordenfelt, 2006; Sverker et al, in press).

In a rehabilitation context, the distinction between ability and performance may be very important. To conceptually and empirically separate aspects of general ability from aspects of actual performance, an integrating additional aspect of performance is needed, i.e. a third qualifier such as the degree of in-

volvement, awareness, the degree of environmental influence, hierarchies of action in terms of for example basic action/action chain, activity/task/occupation or act/task/societal involvement, the degree of interaction, power, formal or informal belonging, and social or economic contexts of an activity (Nordenfelt, 2003; Nordenfelt, 2006; Badley, 2008; Sverker et al., in press). In order to explore the relevance of different approaches that focus on general ability, actual performance and an aspect of perceived involvement, this thesis used a selection of 68 items from all nine life domains of the ICF list of life activities, and all 68 items were explored regarding ability, performance and importance.

The integrative approach

Data from study II showed high correlations between perceived ability and performance regarding 41 % of the 68 items. Among the domains with a rather high proportion of correlations between perceived ability and performance, the two domains general tasks and demands, and communication include items which could be conceived as basic acts. As discussed by for example Coster & Khetani (2008), such items may be embedded in more complex participation. Such basic activities would not be expected to vary very much by culture and would only be influenced by the environment to some extent (Badley, 2008). Some of these basic acts may be performed automatically if one has the ability, and might be difficult to define in terms of frequency and thus also be difficult to get knowledge about by assessing the actual performance. For example in the domain general tasks and demands (study II), the item handling stress showed high correlation between ability and performance which implies that if the person have the ability to handling stress it will be automatically done. The other items of the domain general tasks and demands (e.g. waking up in the morning, getting in time, going to bed in the evening) showed low or moderate correlations which imply a more complex relation between ability and performance (Greenspan et al., 2011; Schalock et al., 2011).

If reflected upon by a person as important parts of a larger project, even quite basic activities, such as learning and applying knowledge, communication, and mobility, should maybe be allowed to affect the total assessment of participation (Nordenfelt, 2003; Nordenfelt, 2006; Sverker et al., in press). Regarding the domain of domestic life, the only item with low correlations between perceived ability and performance was related to acquiring and furnishing a place to live. In a clinical perspective, this is an important aspect of participation and in terms of the distinctions discussed by Badley (2008), a project such as acquiring a place to live may be quite dependent on interactions with environmental attitudes and socio-economic factors (Arvidsson et al., 2008; Buntinx & Schalock, 2010, Greenspan et al., 2011; Schalock, 2011).

The domains are listed and structured on an approximate order of increasing complexity with respect to expected sequences of actions and interactions with the social environment, both regarding the order of domains and within domains (Badley, 2008; Coster & Khetani, 2008). However, analyses of correlations between ability and performance in study II showed the lowest frequencies of items with high correlation in domain 1 and 9; not any item from the domain 9) community, social and civic life and only 17% of the items in the domain 1) learning and applying knowledge were highly correlated between ability and performance. Thus, at least for the studied target group of this thesis, it seems difficult to determine which domains that should be considered as non-complex or as parts or a larger project only on the basis of the pre-assumed complexity (Nordenfelt, 2003; Nordenfelt, 2006; Badley 2008; Sverker et al., in press).

According to the different options described in annex 3 of the ICF, some researchers may argue that not all 68 investigated activities from all nine life domains should be defined as aspects of participation, (WHO, 2001; Badley, 2008). However, the thesis used the whole range of the described 68 items as possible aspects of participation because it is still not clear how to assess participation in a way that pays heed to both the individually relevant spectrum of issues in different groups and environments, and of integrative interdisciplinary disability theory (Bickenbach et al., 1999; Law, 2002; Nordenfelt, 2003; Bhaskar & Danermark, 2006; Nordenfelt, 2006; Thyberg et al., 2010; Sverker et al., in press). Also, the awareness of such activities may vary, for example depending on whether they are perceived as problematic or not; the performance of an activity may be quite simple for other persons but not for people with intellectual disability (Schalock et al., 2011).

Activity and participation

In this thesis, there are results that might suggest that not all 68 items should be considered as participation according to research focusing on the ICF possibility to make a split between different items of activity/participation component in terms of activity *or* participation (WHO, 2001; Badley, 2008). For example in study II, correlations for perceived ability, performance and perceived importance showed higher frequency of items with high correlation between ability and performance in domains 1-4 and higher frequency of items with high correlation between performance and perceived importance in domains 5-9. This finding could be interpreted to support that domains 1-4 could be considered as activity and domain 5-9 as participation in sense that the former would more often performed as a routine, almost without being aware of doing it a person has the corresponding ability. However, an assumption that an activity is performed "almost automatically" does not mean that it is not performed in a social context (Nordenfelt, 2003; Gustavsson, 2004; Nordenfelt, 2006). Thus, it seems reasona-

ble to explore the whole activity/participation list as possible aspects of participation. The latter approach is supported by the finding that in study III the list of highlighted activity items for measures of participation and participation restrictions were a mix of items from all nine domains and no pre-domination for either domain 1-4 or 5-9 were found).

Findings in study II and IV from analyses of internal consistency of the whole scales (68 items) for perceived ability, performance and perceived importance, showed generally high internal consistency however best regarding perceived ability and less good regarding perceived importance. It is not easy to know how people perceive their ability to perform different activities, especially activities that are not preformed often. Among contextual factors personal factors, such as self-efficacy, i.e. believing that one is able to do things, may influence the perceived ability (Maddux, 2002). Self-efficacy is influenced by experienced from the performance of activities and to some extent it also influenced by environmental factors such as attitudes and verbal support. In ordinary language words such as ability, capacity and capability are often used interchangeably. In the ICF terminology, capability is mot used and capacity is used to denote ability in a standardized situation. In this thesis, the term ability is used according to the ICF terminology, i.e. to denote ability without assuming that there is a standardized situation (WHO, 2001).

Earlier drafts of the ICF considered activity and participation as two different dimensions but this distinction was difficult to verify empirically (Perenboom & Chorus, 2003; Reed et al., 2005). Regarding analyses of internal consistency (study II and IV), the all through better consistency of perceived ability, also for specific domains, might indicate that the list of the activity/participation component was constructed from a general ability perspective rather than with respect to actual performance (WHO, 2001; Perenboom & Chorus, 2003; McConachie et al., 2006). A measure of participation will reasonably have to pay heed to environmental influences as well as personal preferences regarding different activities.

The contribution of perceived importance

Common to most definitions of participation are the aspects of actual attendance in everyday situations and/or the aspect of perceived involvement (Maxwell, 2012c). In this thesis, the attendance aspect is measured as the actual performance which is considered as an 'observable' measure such as actually being in a situation and/or actually executing an action (Reed et al., 2005; Nordenfelt, 2006; Arnadottir et al., 2011; Coster et al., 2012; Falkmer et al., 2012; Maxwell, 2012c). The aspect of perceived involvement is measured as the perceived importance which is considered as a 'subjective' measure reflecting the motivation or volition to execute the action (Simeonsson, et al., 2001; Nordenfelt, 2003;

Molin, 2004; Nordenfelt, 2006; Arvidsson et al., 2008; Maxwell et al., 2012b). Hence, aiming at exploring participation and participation restriction according to the ICF, the relation between and combination of the actual performance and perceived importance is essential to explore.

In a clinical perspective, an assessment of participation should pay attention to identifying needs and outcomes regarding relevant areas of intervention. In a theoretical perspective, the assessment should pay heed to the ICF integrative and interdisciplinary model of disability, which integrates the focus of individual, or so called medical models, with environmental, or social, models of disability (Bickenbach et al., 1999; Gustavsson, 2004; Bhaskar & Danermark, 2006; Shakespeare, 2006; Thyberg et al., 2010). According to the latter, participation must not a priori be viewed as a characteristic of a person but as an aspect of functioning and disability that is situated and influenced by varying social contexts. Whereas assessments of body functions may rely on biometrics and a psychometric approach may be optimal for assessments of the general ability to perform a certain set of tasks in a more or less standardized situation, assessments of participation must pay attention to contextual factors (Bickenbach et al., 1999; Gustavsson, 2004; Bhaskar & Danermark, 2006; Thyberg et al., 2010; Stuart, 2012); the possible influence from the social context may affect the choice of assessment strategies and levels of measurement (WHO, 2001; Verdonschot, de Witte, Reichrath, Buntinx & Curfs, 2009; Küçükdeveci et al., 2011; Maxwell, 2012a).

Study II of this thesis reveals low average correlations between ability measures and measures of the perceived importance of the same activities. It indicates that the perceived experience of involvement would be a qualifier distinct from the ICF capacity qualifier. Measures representing the performance qualifier have moderate to high correlations with measures representing ability. Study II suggest that a performance qualifier and an importance qualifier may be used to characterize participation if explicitly operationalized as frequency of participation in activities in life situations in combination with importance.

Findings from Maxwell & Granlund (2011) presented in study I show that several documents mentioning participation are focusing on environmental issues related to civil rights such as availability and accessibility rather than on the subjective experience of involvement. Data in this thesis (particularly in study III and IV) confirm that actual performance may well be sufficient to assess participation if the main interest is at a group level and if the main questions are focused on frequency of involvement. Actual performance seems to be a suitable reflector of attendance aspect of participation and may capture aspects of formal availability and accessibility. Thus, the performance aspect solely might be essential in, for example, services concerned about legal rights and public health.

In a clinical context, however, for example in planning and evaluating supportive interventions, the individuals' own perceptions of involvement are critical. Data in study III and IV show that the result partly differs if the measure of actual performance is combined with perceived importance. These combinations, expressed as important participation and important participation restriction, are considered to capture both the attendance aspect of participation and the perceived involvement aspect. Thus, they seem to be appropriate reflectors of a clinically relevant aspect of participation. The contribution of the perceived aspect is most obvious in the measure of 'important participation restriction'. Even though the measures of low performance solely and 'important participation restriction' (low performance in combination with the subjective perception of high importance) are to some extent highlighting the same domains, 9) community, social and civic life and 7) interpersonal interactions and relationships, the specifically highlighted items differ. Only the activities visiting cinema, visiting restaurants or cafés and relating with strangers are seen in both ranking lists (table 4 in study III). The measure of 'important participation restriction' highlights items such as making a holiday trip, visiting countryside areas, engaging in hobbies, relating with brothers/sisters, relating with parents, relating with friends, establishing friendships, handling stress, driving car, residing as preferred, and working for payment. The measure of low performance solely highlights items such as visiting church, visiting library, engaging in associations, engaging in culture, engaging in sports, engaging in games, relating with neighbours, and maintaining intimate relationship. A possible explanation is that the former items have more value according to perspective of the informants than the items highlighted by the measure of performance solely. Of course, the generalizability to people with a mild intellectual disability in general has to be further explored.

Participation and general well-being

What is the relation between participation and general well-being? In this thesis, study III partly explored frequencies of ratings of performance and performance in combination with perceived importance as well as the correlations of these measures with subjective general well-being. The results showed moderate positive correlations and this finding is similar to findings from validation studies that compare single-item measures of subjective general well-being to multi-item measures of well-being (Diener, 2009; Paiva & Paiva, 2011; Stiel et al., 2011).

The strength of correlations values must of course be interpreted carefully but the finding may be regarded as a rough client-oriented validation of the measures of participation. Although the correlations were not weak, the coefficients indicate that the biggest part of the variation is probably explained by other factors. However, the correlations are clinically interesting because they are probably not explained by conceptual similarities, which could have been the case if participa-

tion were related to for example a quality of life instrument containing a selection of specific items that could be linked to the activity/participation component of the ICF (Cieza et al., 2002; Granlund, Eriksson & Ylvén, 2004; Thyberg et al., 2012).

What is "full" participation?

There are quite different models of functioning and disability, and different ways to think about well-being, disabling/enabling influences and mechanisms (Gustavsson, 2004; Bhaskar & Danermark, 2006), and people may use different strategies when constructing their perceptions of general well-being (Pavot & Diener, 1993; Diener, Lucas & Oisho 2002; Diener, 2009). In the ICF terminology (annex 1 of the ICF), well-being is a general term encompassing the total universe of human life domains that make up what can be called a 'good life' (WHO, 2001). ICF is intentionally composed by a careful selection of activities perceived as health promoting, important and socially accepted and not composed by any activities regarded as for example self-destructive or anti-social, (WHO, 2001). The finding in study III, that 52 of the 68 items were perceived as important by 50 % or more of the informants, may be considered as a confirmation of the relevance of that intention.

But what is "full" participation? Is the ICF activity/participation list useful in order to know what should be assessed to find out if a person has low or high levels of participation? In, for example, the domain of major life areas three of the five items that were included in the questionnaire of this thesis represented studying, apprenticeship, and working for payment respectively. In a Swedish context, few persons with a mild intellectual disability would be expected to perform more than one of these three activities during the same period of life. Even if they are strongly related in terms of the ability aspect they might not be statistically related in whether they will actually be performed by the individual or even considered as important. This discussion highlights a general problem concerning assessments of participation: What is really high or low participation? What is an acceptable participation and when should it been considered as not-acceptable? And would such a measurement be reasonable without including the individual aspect of perceived importance (Katz et al., 2006)? It seems reasonable that a high opportunity and high availability and accessibility to perform activities would be enhancing health and well-being. Thus, for example, for in public health context, a generally high opportunity/availability/accessibility of a socially or technically supportive environment would increase the general frequency of performance, in a range of life domains, for people a mild with intellectual disability as a group. For specific individuals, however, the most enhancing factor would be high opportunity/availability/accessibility to perform activities that he or she actually wants to perform or is in a need to perform. What are

the specific needs of support for the specific individual? To know this, knowledge about the perceived aspect of involvement is required.

The relation between self-ratings and proxy ratings

Performance and importance

This thesis does not evaluate the relation between the self-ratings and proxy-ratings in terms of right or wrong, but addressed a need to be aware of similarities and difference in clinical reasoning. Findings from study IV indicate that the perceived aspect of participation should, if possible, be assessed by the individual. Study IV showed no significant differences between mean scores of performance solely or of 'important participation'. In this regard, the measure that combined high performance and high importance did not seem to add any information to the measure of performance solely. For the measure that combined low performance and high importance, however, significant differences between self-ratings and proxy-ratings of importance and of 'important participation restriction' were found. Hence, for an assessment of participation restrictions the perceived aspect of involvement seems essential.

Study IV also showed significant differences between self-ratings and proxy-ratings of importance and of 'important participation restriction' but no significant differences between mean scores of performance solely or of 'important participation'. These findings indicate a good match between self-ratings and proxy-ratings for the frequency of actual performance in different activities but that it is difficult for a proxy-person (i.e. a relative or staff person) to estimate the individual's perceived importance or perceived participation restriction of different activities. Thus, for a proxy-person it is difficult to estimate if a not often performed activity is important to the individual or not. This supports conclusions from earlier studies that, when it comes to identify perceived disability and to design individual support, self-rated data is preferable provided the existence of such data (Snell et al., 2009; Thompson et al., 2009; Claes et al., 2012a). Data of proxy-ratings might still be useful as a complement, especially when proxies are a part of the supportive intervention (Claes et al., 2012a; Tassé et al., 2012), but it seems to be difficult for another person than the individual him-/herself to get full knowledge about the reason for low performance, i.e. whether it is due to ability, availability, perceived importance, perceived will or anything else. The aspect of perceived disability is clinically essential in identifying problems in relation to rehabilitation goals (Walsh, 2008; Thompson et al., 2009; Buntinx & Schalock, 2010; Arnadottir et al., 2011; Snell et al., 2012; Tassé et al., 2012).

Ability

Results of paired samples of self-ratings and proxy-ratings for general ability in study IV might be at interest for intervention planning and evaluation. The findings in study IV showed that approximately 52 items were rated high by persons with intellectual disability and approximately 48 items were rated high by proxy-persons. Although this difference is statistically significant, it should not be over-interpreted. Some activities are of course more difficult to estimate than others. It is easy to rate if a person can ride a bike or not but it is more difficult to rate a person's ability regarding relations to friends. However, if these findings may imply that proxy-persons might have difficulties to get knowledge about the persons' ability in activities which are not often performed and/or not perceived to be important.

Another possible interpretation is that persons with intellectual disability may have a tendency to overestimate their ability in an attempt to appear more capable than they may actually be (Finlay & Lyons, 2002; Greenspan et al., 2011; Tassé et al., 2012). Such an overestimation has been discussed in terms of coping strategies, attempts to hide the disability, and to pass as "normal" by trying to appear capable (Snell et al., 2009; Claes et al., 2012a). As a coping strategy, it may be more effective for the person to give the impression of having the skill or ability to perform a certain action, rather than to actually perform the action with the risk of failing (Snell et al., 2009; Claes et al., 2012a). The resulting similarity in mean scores between self-ratings and proxy-ratings of performance in combination with the resulting differences for general ability support such a notion. This strategy to handle the perceived disability might even embrace rejections of suggested accommodation and support that could have been available if the disability had been declared (Snell et al., 2009; Claes et al., 2012a; Stuart, 2012; Tassé et al., 2012). If the person disclaims support it might influence his or her global well-being and psychological health and, in its turn, his or her participation (Arvidsson et al., 2008; Thompson et al., 2009; Buntinx & Schalock, 2010). Even though these last interpretations are tentative, and even though this thesis has not studied the relation between participation/participation restrictions and perceived needs and seeking/rejecting support, the findings may be important to be aware of in clinical supportive situations.

Conclusions

In order to understand differences between the ability and the degree of actual performance of activities listed in the ICF, a third qualifier such as the degree of involvement or perceived importance is useful.

Ratings of performance and perceived importance, as well as the ratings ability, should be regarded as in a context. The relation between ability and performance is considered as a continuum with ability at the first end-point, via actual performance, to perceived involvement at the other end-point. This continuum of aspects is explored without any a priori distinction between activity and participation and the term activity is used just to denote the ICF list of things that people may do.

If the main interest of participation is at a group level and if the main questions are focused on frequency of involvement, actual performance may well be sufficient to assess participation. The performance aspect solely might be essential in for example services concerned about legal rights and public health.

If the individuals' own perceptions of involvement are critical such as in planning and evaluating supportive interventions, a measure of actual performance in combination with perceived importance is needed. These combinations, expressed as important participation and important participation restriction, are considered to capture both the attendance aspect of participation and the perceived involvement aspect.

The contribution of the perceived aspect of involvement is most obvious in the measure of 'important participation restriction', i.e. low performance in combination with high perceived importance.

When it comes to identify perceived disability and to design individual support, self-rated data is preferable provided the existence of such data.

Svensk sammanfattning (Summary in Swedish)

Varför har avhandlingen gjorts?

Personer med lindrig utvecklingstörning löper en större risk att få både kroppsliga och psykologiska hälsoproblem i jämförelse med andra. Att ha en lindrig utvecklingsstörning innebär också att man ofta upplever sig hindrad att göra saker man vill i sin vardag och man lever ofta också ett mer utsatt socialt liv. Med begreppet *lindrig* menas att personen har lindrigare kognitiva/intellektuella nedsättningar jämfört med personer med måttlig eller grav utvecklingsstörning. Det menas *inte* att man har lindrigare problem i vardagen, snarare kan det många gånger vara tvärtom, att man upplever större problem i vardagen.

I forskning har man jämfört hur personer med lindrig utvecklingsstörning har det i sina liv med hur ”människor i allmänhet” har det i sina liv. Där har man sett stora skillnader inom i stort sett alla livsområden, framförallt när det gäller arbetsliv, inkomstförhållanden och socialt umgänge. Personer med lindrig utvecklingstörning får ofta sina pengar från det offentliga socialförsäkringssystemet och de har ofta svårt att påverka sin ekonomi. Ett annat stort problem gäller det sociala umgänget. De flesta vuxna personer med lindrig utvecklingstörning umgås bara socialt med anhöriga och/eller personal. Få har riktiga vänner, alltså vänner som de själva har valt att umgås med.

Forskning och erfarenhet visar att nyckeln till ett förbättrat liv för personer med lindrig utvecklingstörning är att det finns stöd att få. För att stödet ska fungera bra måste det dock vara väl anpassat till varje individs upplevda behov. Nationella översyner av hur stödet fungerar visar att det finns ett glapp mellan det stöd som erbjuds och det behov som personer med lindrig utvecklingstörning upplever. Ett stort problem är att personerna själva inte alltid tycker att stödet finns till för dem eller att det är just det stödet som erbjuds som de vill ha. Detta beror förstås till viss del på bristande resurser, men också på bristfälliga kunskaper/metoder hos de personer som ska ge stödet.

Personer med lindrig utvecklingstörning kan ha nedsatt förmåga till att *förstå* sina egna begränsningar. De kan också ha svårt att *värdera* vilka behov som är viktigast. Dessutom kan de ha nedsatt förmåga till att *uttrycka* och *förklara* sina stödbehov. Som en följd av detta blir personer med lindrig utvecklingstörning ofta beroende av anhöriga och/eller personal. Det blir ofta någon annan än personen själv som får förklara vilka stödbehov som finns. Detta gäller i hög grad i kontakter med sjukvård och myndigheter, även i kontakt med habiliteringen. Det är därför en viktig uppgift för alla verksamheter som möter personer med lindrig utvecklingstörning att utveckla, anpassa och verkligen använda metoder som underlättar för den enskilde att själv uttrycka sina behov. Dessa metoder kräver

både tid och kunskap att använda. Det är därför väldigt ”lätt” att istället gå ”genvägen” via till exempel den person som följer med till mötet/mottagningen.

ICF och delaktighet

I ICF (Den internationella klassifikation av funktionstillstånd, funktionshinder och hälsa) används begreppet *delaktighet* för att beskriva hur människor agerar och fungerar i sitt liv. ICF menar att funktionshinder orsakas av *både* kroppsliga orsaker *och* av samhället. En persons delaktighet är därför en konsekvens av *både* kroppsliga nedsättningar *och* brister i omgivningen. Denna syn på funktionshinder och delaktighet passar att använda för personer med lindrig utvecklingsstörning. ICF definierar delaktighet som en persons ’engagemang i en livssituation’. När en person upplever hinder i vardagen, till exempel upplever svårigheter att förklara sina behov i mötet med sjukvården, kallar ICF detta för *delaktighetsinskränkningar*. ICF definition av delaktighetsinskränkningar är ’problem som en person kan ha i engagemang i livssituationer’. ICF har en lista över en mängd olika saker en person kan vara delaktig i. Listan är indelad i nio olika livsområden, från saker som har med lärande och grundläggande kommunikation att göra till saker som har att göra med hur man tar del av det omgivande samhället. Däremellan finns saker som personlig vård, förflyttning, hemliv, arbete/skola/fritid och sociala relationer.

Delaktighet och delaktighetsinskränkningar enligt ICF anses vara viktiga begrepp för att spegla vilka behov av stöd en människa kan ha. ICF föreslår att faktorn *genomförande* (vad personen gör) ska användas för att bedöma delaktighet. Men för att ge ett bra stöd till personer med lindrig utvecklingsstörning behövs kunskap om hur de själva *upplever* sina behov. Bedömer man delaktighet på det sättet som ICF vill får man bara kunskap om saker som personen *faktisk gör*. Man får inte kunskap om personen tycker saken är *viktig* eller om det finns andra saker som han/hon skulle vilja göra. Det finns därför ett behov av att utveckla en metod som också fångar personens *upplevelse* av sin delaktighet och inte bara vad han/hon faktiskt gör. Den här avhandlingen är ett försök att undersöka hur ett sådant sätt att ”mäta” delaktighet genom att ställa frågor om både vilka aktiviteter personen *gör* och om aktiviteten upplevs som *viktig* eller inte.

Det övergripande vetenskapliga syftet med avhandlingen var att utveckla och undersöka hur delaktighet enligt ICF kan mätas på personer med lindrig utvecklingsstörning. Avhandlingen består av fyra delarbeten som tillsammans svarar på de här tre övergripande forskningsfrågorna: Hur kan delaktighet enligt ICF mätas? På vilket sätt bidrar måttet *upplevd viktighet* till ett mått på delaktighet? Hur ser relationen ut mellan självskattningar och skattningar gjorda av närstående när det gäller olika mått på delaktighet?

Kort beskrivning av avhandlingens metod

Deltagare

I studie II deltog 55 personer med lindrig utvecklingsstörning och i studie III deltog 69 personer. I studie IV deltog 40 personer med lindrig utvecklingsstörning samt lika många anhöriga och/eller personal. Samtliga deltagare hade någon form av stöd från samhället, till exempel särskola, daglig verksamhet och/eller stöd i sitt boende. De var i åldrarna 16-40 år.

Mätinstrument

Studie I gjordes för att få bättre kunskap om hur delaktighet kan mätas genom att också använda sig av ett mått hur delaktigheten upplevs av individen själv. I studie I användes resultat från flera projekt för att undersöka hur delaktighet kan mätas.

I resten av studierna (II-IV) användes ett urval av 68 vardagsaktiviteter (se bilagan i slutet av denna svenska sammanfattning). De 68 vardagsaktiviteterna analyserades på lite olika sätt för att undersöka hur delaktighet kan mätas hos personer med lindrig utvecklingsstörning. Mätningarna gjordes genom att direkt fråga personer med utvecklingsstörning. Frågorna ställdes som: Hur ofta *gör* du aktiviteten? Hur *viktig* är aktiviteten för dig? Frågandet kan beskrivas som en hårt strukturerad intervju eller muntlig enkät. I några av studierna frågades det också om den upplevda *förmågan* att utföra aktiviteten. Frågan ställdes som: *Kan* du göra aktiviteten?

I studie IV ställdes exakt samma frågor om de 68 vardagsaktiviteterna till en närstående, alltså en anhörig eller personal. Detta var för att kunna jämföra självskattningarna med närståendeskattningar.

I studie III ställdes det också en fråga om hur personen tyckte sig må rent allmänt i livet. Denna fråga mätte personens *allmänna välbefinnande* och ställdes för att undersöka om delaktighet verkar hänga ihop med hur en person mår i största allmänhet.

Analyser

Det gjordes statistiska beräkningar för att analysera om deltagarna i studierna verkar kunna hålla isär frågorna om *kan*, *gör* och *viktigt*. Detta var en viktig analys för att veta om metoden är pålitlig överhuvudtaget. Dessa analyser gjordes framförallt i studie II men även i studie IV.

I studie III gjordes beräkningar av hur *delaktighet* och *välbefinnande* hänger ihop. Det gjordes analyser för att se om det blev några skillnader i resultat, om måttet på den upplevda viktigheten användes eller inte. För att undersöka detta närmare jämfördes också olika rankinglistor på de olika vardagsaktiviteterna. Detta var också i studie III och där fanns till exempel två listor över *delaktighets-*

inskränkningar. Den ena listan byggde på att personerna svarat att de *inte gör aktiviten ofta*. Den andra listan byggde på att personerna svarat att de *inte gör aktiviteten ofta men tycker den är viktig att göra*.

Slutligen gjordes det i studie IV beräkningar för att analysera skillnader och likheter mellan självskattningar och närståendeskattningar.

Avhandlingens viktigaste resultat

Resultat i studie II visade att deltagarna skiljer på de olika måtten kan, gör och viktigt. Resultatet talar för att självskattningsmetoden är pålitlig för att mäta delaktighet. Skillnaden mellan skattningarna av gör och viktigt var dock lite mindre vilket leder till att man kan tänka att de är två aspekter av ett underliggande begrepp, att *gör* och *viktigt* är två aspekter av *delaktighetsmåttet*.

Resultaten från studie III visade att självskattat *välbefinnande* var relativt högt korrelerat till olika mått på *delaktighet*. Det betyder att de som skattar att de har hög delaktighet också mår bra och att de som upplever delaktighetsinskränkningar mår sämre. Sambanden gällde oavsett om delaktighet mäts bara som *gör* eller om det kombineras med måttet på upplevd *viktighet*.

Rankinglistorna över aktiviteter i studie III visade dock på ganska stora skillnader för *delaktighetsinskränkningar* om måttet på upplevd viktighet fanns med eller inte. På listan som baserades enbart på vad deltagarna sällan gör kom följande aktiviteter högst upp (gjordes mest sällan): gå på gudstjänst, umgås med grannar, besöka biblioteket, skriva brev till myndigheter och laga sina kläder. På listan som baserades på vad deltagarna sällan gör men ändå upplever som viktiga kom följande aktiviteter högst upp: åka på semester, hantera stress, köra bil, bo som man vill och att umgås socialt med vänner och syskon. Den senare listan bedömdes vara kliniskt mer relevant ur ett stödperspektiv.

När det gäller de 68 utvalda aktiviteterna som studerats närmare i denna avhandling så tyckte över hälften av deltagarna i studie III att 52 av de 68 aktiviteterna var *viktiga*. Detta tolkades som att listan av aktiviteter är bra att använda vid mätning av delaktighet.

Resultaten från studie IV visade att när det gäller frågor om vad personen faktiskt *gör* så skattar personen själv och den närstående ungefär lika. När det gäller hur *viktig* aktiviten upplevs vara var överenstämmelsen sämre. Även skattningarna av delaktighetsinskränkningar (att tycka ett en aktivitet är viktig men ändå inte göra den) visade på sämre överensstämmelse.

Avhandlingens viktigaste slutsatser

Avhandlingen visar att det finns begränsningar med att mäta delaktighet enbart med måttet gör. Är man intresserad av att få veta mer om personens egen uppfattning om sin delaktighet behövs ett tilläggsmått på hur personen upplever sin

delaktighet i aktiviteten. Ett bra delaktighetsmått kan således vara att *kombinera* det faktiska genomförandet men den upplevda viktigheten

Avhandlingen visar att delaktighet kan mätas genom fråga *hur ofta* en person utför en viss aktivitet och *hur viktig* aktiviteten upplevs vara. Om aktiviteten är viktig och samtidigt utförs ofta kan man säga att personen har en hög *delaktighet* i den aktiviteten. Om aktiviteten är viktig men inte görs så ofta som personen vill eller behöver kan man säga att personen har en *delaktighetsinskränkning* i den aktiviteten.

Genom att fråga om alla de 68 aktiviteterna får man en bra bild av personens delaktighet och delaktighetsinskränkningar. Detta eftersom de 68 aktiviteterna täcker av ICF nio livsdomäner. De sammanlagda svaren ger därför god kunskap om vilka behov en person upplever i sin vardag. Att mäta delaktighet på det sätt som studeras i avhandlingen kan därför vara användbart i sammanhang där stöd ges till personer med lindrig utvecklingsstörning.

Sammantaget visar avhandlingen att självskattningar är ett pålitligt sätt att mäta delaktighet enligt ICF hos personer med lindrig utvecklingsstörning. Det kan gå att fråga närstående också men om man vill veta mer ingående hur en person upplever sina behov är självskattningar att föredra.

Bilaga till den svenska sammanfattningen - de 68 aktiviteterna indelade efter livsområden

1. Lärande och tillämpa kunskap
Se på TV eller se en film? Lyssna på musik? Läsa en tidning? Läsa en bok? Skriva för hand? Skriva på dator?
2. Allmänna uppgifter och krav
Vakna på morgonen? Komma i tid till jobbet/skolan? Passa andra tider? Gå och lägga dig på kvällen? Hantera stress?
3. Kommunikation
Förstå innehållet i en dagstidning? Förstå ett nyhetsprogram på TV? Förstå vad som sägs på radion? Delta i en diskussion? Skriva brev till en myndighet/sjukvården? Använda dig av en vanlig telefon? Använda dig av mobiltelefon (för att prata)? Använda dig av e-post/SMS?
4. Förflyttning
Plocka upp en liten sak som du tappat? Gå en promenad? Cykla en runda? Åka bil? Åka buss, tåg eller flyg? Köra bil?
5. Personlig vård
Tvätta dig eller duscha? Borsta tänderna? Sköta hår och naglar? Gå på toaletten? Klä på och av dig? Äta och dricka? Veta vad du skall äta för att må bra? Veta hur du skall sköta dig för att hålla dig frisk?
6. Hemliv
Bo hur du vill? Handla det du vill ha? Laga din egen mat? Tvätta dina kläder själv? Städa själv? Laga dina kläder om de går sönder? Byta en glödlampa/byta gardiner? Hjälpa någon annan som ber om hjälp?
7. Mellanmänskliga interaktioner och relationer
Umgås med vänner? Vara med människor du inte känner? Skaffa nya vänner? Förstå andra människors kroppsspråk? Umgås med t.ex. klass-/arbetskamrater? Umgås med personal/lärare? Umgås med dina föräldrar (eller motsvarande)? Umgås med dina syskon? Umgås med grannar? Ta kontakt med en människa du är nyfiken på? Ha en pojkvän/flickvän/ partner?
8. Viktiga livsområden
Gå i skolan/utbilda dig? Ha en praktikplats? Arbeta och tjäna pengar? Betala dina räkningar? Ta hand om dina pengar själv?
9. Samhällsgemenskap, socialt och medborgerligt liv
Vara med i en klubb/förening? Spela spel/delta i lekar? Delta i idrott? Delta i kultur (t.ex. teater, spela musik)? Ha en hobby (sy, måla mm.)? Gå på restaurang/ kafé? Gå på bibliotek? Gå på bio? Gå i kyrkan/gå på politiska möten? Vara ute i naturen? Åka på semester?

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